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Participant-produced photography to augment therapeutic
interventions for people with intellectual disabilities



Natalie E. Boulton

North Wales Clinical Psychology Programme

Thesis submitted in partial fulfilment of the regulations for the

Doctorate in Clinical Psychology

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Thank you to the participants, supporters and community ID teams who took part in this research. Without your enthusiasm and perseverance, this thesis would not have been possible.

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To my family and friends: I'm sorry that this has taken me away from you for so long. Thank you for always being there and supporting me in everything I do. I am eternally grateful for your unwavering support.

We got there in the end.

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Could participant-produced photography augment therapeutic interventions for people with intellectual disabilities? A narrative review of the available evidence

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Thesis Abstract

This thesis explores the feasibility of participant-produced photography to augment therapeutic interventions for people with intellectual disabilities (ID). A systematic literature review was undertaken to determine the evidence base underpinning the use of participant-produced photography within therapeutic settings. A systematic search of peer-reviewed journals identified 13 relevant papers. Participant-produced photography showed promise, although evidence pertaining specifically to people with ID was sparse. The review concluded that participant-produced photography within therapeutic settings showed promise for people with ID. However, methodological implications rendered it difficult to derive firm conclusions regarding the effectiveness of different approaches.

The empirical study undertook a component-analysis, focusing on the ‘values’ element of the Acceptance and Commitment Therapy (ACT; Hayes et al., 2011) treatment package. A multiple baseline across participants design ($n = 6$) was implemented. Self-reported ratings of anxiety, mood, experiential avoidance and life satisfaction were collated via text message every three days. Visual inspection and preliminary statistical analysis of the multiple baseline data indicated minimal effectiveness of a values-based approach in isolation.

Photography facilitated clarification of the concept of values. Empirical findings suggest that value-based intervention may be necessary, but not sufficient for therapeutic change. The data are suggestive of relationships that warrant further scrutiny. The study lends support to the use of novel approaches such as photography and text-message data collection for intervention research with people with intellectual disabilities.

The findings highlight the potential feasibility of a value-based approach for people with ID, augmented through the use of participant-produced photography to enhance conceptual understanding of the values component of ACT. The authors consider this to be a logical, preliminary step towards the initial basis of an ACT- ID evidence base. Implications for future research and clinical practice are further explored.

Chapter 1 – Literature Review

Could participant-produced photography augment therapeutic
interventions for people with intellectual disabilities?

A narrative review of the available evidence.¹

¹ This chapter formed the basis of a paper submitted to the Journal of Intellectual Disabilities (Boulton, Williams & Jones). Could Participant-Produced Photography Augment Therapeutic Interventions for People with Intellectual Disabilities? A narrative review of the available evidence. Journal submission guidelines are contained at the start of this chapter.

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REVIEW ARTICLE

Could participant-produced photography augment therapeutic interventions for people with intellectual disabilities? A narrative review of the available evidence.

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Abstract

Background: People with intellectual disabilities are entitled to equitable access to psychological support. Traditional therapeutic approaches often rely on a person's ability to verbally articulate a description of their life, which can be particularly difficult for emotionally salient information.

Methods: A systematic literature review was undertaken to determine the evidence base underpinning the use of participant-produced photography within therapeutic settings. Evidence across a range of specialisms was examined in order to extrapolate areas of best practice and make recommendations for its implementation alongside people with intellectual disabilities.

Results: A systematic search of peer-reviewed journals identified 13 relevant papers. Participant-produced photography showed promise, although evidence pertaining specifically to people with intellectual disabilities was sparse.

Conclusion: Participant-produced photography within therapeutic settings shows promise for people with intellectual disabilities. Methodological limitations made it difficult to derive firm conclusions regarding the effectiveness of different approaches. Implications for clinical and research practice are discussed.

Key words: Camera; Literature Review; Participant-produced photography; Photos; Therapy

Could participant-produced photography augment therapeutic interventions for people with intellectual disabilities? A narrative review of the available evidence.

1. Introduction

1.1. Background

Equitable access to psychological support is important for people with intellectual disabilities; and yet, many traditional therapeutic approaches rely on didactic interviewing methods. Taking about life in this way may prove difficult for some people with intellectual disabilities. Challenges posed by verbal articulation of emotional experiences may affect meaningful engagement with therapeutic ventures. Further research is necessary in order to explore how language-based therapies may be augmented to enable people with intellectual disabilities to actively engage with and yield meaningful benefits from therapeutic processes.

Essentially, this requires a willingness to develop therapeutic approaches alongside people with intellectual disabilities, according to individual needs, levels of functioning and cognitive ability. By consideration of factors including mode of delivery and facilitative engagement, clinicians may develop tailored therapeutic interventions through which creative collaboration may flourish. One such way is participant-produced photography.

1.2 Participant-produced photography for people with intellectual disabilities

Photography has been used for many years within therapeutic settings to facilitate growth and change (Stewart, 1979; Noland, 2006; Steger et al., 2013). Taking photographs of valued aspects of life and sharing them within therapeutic settings is thought to serve to overcome barriers, permitting choice and empowering individuals to portray their unique world perspective (Graf, 2002). Photographs produced by people with intellectual disabilities have the potential to provide a natural channel for exploration of life-meaning, values and purpose (Lewis & Lindsay, 2000). Tangible in nature, photography requires minimal training or sustained effort.

Numerous claims have been made regarding the effectiveness of photography in a therapeutic environment. Beyond convenience, photography has been claimed to enhance self-awareness (Glover-Graf, 2000; Hagedorn, 1994; Oneha, 2001), enhance memory recall (Stewart, 1979; Land Smith, Park, Beabout & Kim, 2009), increase sense of ownership in the therapeutic process (Noland, 2006; Brown, Worrall, Davidson & Howe, 2012) and capture experiences often inaccessible through language alone (Enzman-Hagedorn, 1996).

A number of authors (e.g. Harper, 1987; 2002) have speculated that, from a neuro-physiological perspective, pictures may evoke deeper elements of human consciousness than words. Within therapeutic settings, photographs may hone attentional focus, whilst encouraging wider exploration (Cosden & Reynolds, 1982; Cook & Hess, 2007). Participant-produced photography may have particular potential as a therapeutic tool for people with intellectual disabilities, allowing individuals to draw on captured images to facilitate a shared understanding of unique, individual experience. The current review will examine

the evidence surrounding these assumptions and make recommendations for future practice.

1.3 Rationale and primary research question

The current review aims to explore the potential utility of incorporating photographs captured by participants into therapeutic settings for people with intellectual disabilities. Given the paucity of published literature pertaining to photography specifically with people with intellectual disabilities, evidence across a range of specialisms will be examined. Recommendations for extrapolation of key findings for people with intellectual disabilities will be discussed. To the authors' knowledge, this is the first review to synthesise literature based exclusively on photographs taken by participants.

2. Methodology

2.1 Eligibility Criteria

Studies were included and excluded based on the following criteria:

Inclusion criteria:

1. Studies published in peer-reviewed journals, in English (no date restrictions applied).
2. Participant-produced photography as an intervention directed at making change at an emotional, educational or behavioural level, according to psychological theory.

Exclusion criteria:

1. Photography for reasons other than to support an intervention (e.g. qualitative research, participatory action research, health-promotion).
2. Descriptive papers/no photographic intervention.

2.2 Search Strategy

A search of PsycInfo, ERIC (Proquest), CINAHL and Medline (via EBSCOhost) was undertaken. Using the same search strategies for each database, the following search terms were used: *“photo,” “photos,” “photograph*,” “photo-therapy,” “phototherapy,” “autophotography,” “auto-photography,” “snap*,” “polaroid,” “camera,” “digital photography.”* Eligibility for inclusion was assessed by title and abstract examination to exclude studies that did not meet criteria. An ancestral search was used to obtain relevant studies not identified by the initial electronic search. The process of study selection is depicted in Figure 1, based upon the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009).

[INSERT FIGURE 1]

2.3 Analysis

Disparities and methodological heterogeneity across identified studies rendered a narrative, rather than meta-analytical, approach most suitable for synthesis of the findings.

3. Results

Following the application of the search strategy and eligibility criteria, 13 studies including 194 participants were identified. Available data was extracted from each paper and collated (See Table 1)

Table 1

Characteristics of included studies

Citation (Country)	Sample Characteristics					Methodological Characteristics			
	N	Mean Age (Range)	% Female	Setting	Mode	Photography Intervention	Measured Outcome	Main Findings/ Conclusions	Limitations/Potential for Bias
Bradbury, Gross, Goodman & Straits, (2010), USA	-	-	-	School: First grade science class	Group	Exploration of science concepts. Duration: 1 school day Frequency: Once Number of photos: - Photographic Equipment: Digital camera	Photographs & PowerPoint presentation.	Photography energised students, enhanced attentional environmental focus and fostered sense of wonder and inquisitiveness.	Demographic data absent. No systematic assessment of pre/post knowledge. Impact of increased socialisation/ engagement with peers not accounted for. No control group.
Davison (2009), USA	-	-	-	School: Primary	Group	Gather photographic evidence during zoo outing. Duration: 1 day Frequency: Once Number of photos: ≥10 Photographic Equipment: Digital Camera (1 per 5/6 students)	Student self- reflection-rubric. Individual student science learning rubric (developed by teacher)	Digital images a powerful tool for construction of meaning.	Author as primary researcher. Sample size/characteristics not reported. Systematic assessment of pre/post outcomes absent. Outcomes not reported. Group processes not controlled/accounted for. No control group.

DeMarie & Ethridge (2006), USA	3	4 (3-5)	66.7	Pre-school	Individual	<p>Photograph typical pre-school day activities.</p> <p>Duration: 1 day</p> <p>Frequency: Once</p> <p>Number of photos required: ≤12.</p> <p>Photographic Equipment: Pocket Instamatic Camera (film of 12 exposures).</p>	<p>Description of pre-school day:</p> <p>Pre: without photographs.</p> <p>Post (2 weeks): With reference to captured images.</p>	<p>Information gleaned doubled with inclusion of photographs (more detail, improved recall and verbal ability).</p>	<p>Small sample size. Children interviewed by “<i>familiar adult</i>.”</p> <p>Systematic assessment of pre/post outcomes absent. Extraneous variables uncontrolled.</p>
Einarsdottir (2005), Iceland	34	5 (4-6)	-	Playschool	Group & Individual	<p>Group 1 (<i>n</i> = 22): Capture images whilst facilitating guided tour of playschool for author.</p> <p>Duration: ‘guided tour’</p> <p>Frequency: Once</p> <p>Number of photos required: -</p> <p>Photographic equipment: Digital camera</p> <p>Group 2: (<i>n</i> = 12)</p> <p>Photograph important aspects of playschool (unsupervised)</p> <p>Duration: 1 school day</p> <p>Frequency: Once</p> <p>Number of photos required: -</p> <p>Photographic equipment: Disposable camera</p>	<p>Photographs.</p>	<p>Photographs alone portray only partial story.</p> <p>Group 1: Photographs of school and play objects.</p> <p>Group 2: Photos of each other, self in mirror, peers playing “<i>having great fun doing something they felt they shouldn’t be doing.</i>”</p>	<p>Teachers as “<i>co-researchers</i>” and interviewers. Minimal demographic data.</p> <p>Author as primary researcher. Number of photos taken by Group 2 not reported.</p> <p>Increased photographic opportunities for Group 2 (longer time with camera).</p>

Elinder, Brunosson, Bergstrom, Hagstromer & Patterson, (2012), Sweden	18	- 23 < 60	55.6	Community Residential/ day centres for people with intellectual disabilities.	Individual (& staff prompts)	Photograph all food/beverages consumed daily. Duration: 3 days Frequency: All eating/drinking occasions. Number of photos: - Photographic Equipment: Digital Camera (Canon PowerShot A480).	Meal quality and dietary diversity. Inter-rater reliability of photos (compared to observer ratings)	85% of eating/drinking occasions photographed (reminders required 40% of time). Excellent correlation between observation by researcher and participant photography score for dietary diversity (ICC = 0.84, $P < 0.001$).	Small sample size. Limited generalisability. Disregarded food not accounted for. No attrition data. Methodology limited to subjects with mild to moderate intellectual disabilities given the need for prompts in 40% of cases.
Germain (2004), UK.	9	16	0	Special Educational Needs School	Individual	Photograph school half-term activities. Duration: 1 week Frequency: Daily Number of photos required: - Photographic equipment: Disposable camera.	Photographs	77.8% camera return rate (lost, $n = 1$, “difficult home circumstances,” $n = 1$). Photography transcended language barriers inherent within didactic interview methods, empowering participants to share their views.	Small sample size. Systematic pre/post outcome measurement absent. No control group. Non-random selection.
Glover-Graf & Miller (2006) USA	5	37 (23 – 51, $SD = 12.9$)	40	Outpatient Clinic: Chemical dependence programme	Group	Black and white photography relating to pre-selected weekly themes Duration: 12 weeks Frequency: Weekly Number of photos required: $\geq 4/5$. Photographic Equipment: “Camera”	Multi-Dimensional Self-Esteem Inventory. Trauma Symptom Inventory (pre-assessment only). Researcher-designed abuse questionnaire.	Improved self-esteem ($n = 4$)	Small sample size. Type of camera unclear. Ethnically homogenous sample (80% Hispanic). Potential impact of treatment within familiar clinic setting overlooked. No control group. Simultaneous receipt of various additional treatment via clinic (e.g. AA support

									group). Effect of group processes on self-esteem overlooked.
Gregory, Walwyn, Bloor & Amin (2005), UK	12	- 44 < 70	66.7	Hospital: Obesity and diabetic clinic	Individual	Record nutritional intake (photographs and food diary) Duration: 3 days Frequency: All eating/drinking occasions Number of photos: 1 per eating/drinking occasion. Photographic equipment: Disposable flash camera.	Self-reported nutritional intake (food diary alone) versus food diary plus photographs.	Estimates of energy intake increased when matched photographs were considered (+83 ≤ +128kcal, <i>p</i> = 0.87). High rate of refusal to participate (<i>n</i> = 18, 60%).	Reliance on participant motivation and honesty. Second helpings/plate-waste not accounted for. Small sample size. Minimal demographic data. No follow-up data based on nutritional feedback. Non-randomised selection. Limited generalisability.
Land, Smith, Park, Beabout & Kim (2009), USA	-	-	-	School: Fifth Grade Health Class	Individual	Photograph all food consumed and record in food diary. Duration: 3 days. Frequency: All eating/drinking occasions Number of photos: - Photographic Equipment: Disposable Camera	Food diary. Student ability to apply nutritional concepts (pre/post).	Statistically significant difference between paired proportions of increasing healthy food and decreasing unhealthy food (one tailed) (<i>X</i> ² = 3.008, <i>P</i> = .04). Photographs prompted recall. Photographs highlighted discrepancies between actual and perceived dietary intake.	No control group. Minimal demographic data. Home circumstances not considered. No follow-up data. Pre/post nutritional knowledge not systematically evaluated.

Mizock, Russinova & DeCastro, (2015), USA	16	-	-	Psycho-social Rehabilitation centre	Group/ Individual	Manualised programme (Recovery Narrative Photo-voice) as a mental health intervention (pilot study with two waves of program delivery). Duration: 10 weeks Frequency: 2 hours, weekly. Number of photos required: - Photographic equipment: -	Wave 1: (<i>n</i> = 8) Ryff Scale of Psychological Wellbeing. Wave 2: (<i>n</i> = 8) The Empowerment Scale, Community Integration Measure	No significant differences noted on any outcome measures. Photographs highlighted transformations along the illness-recovery continuum. High attendance rates (Wave 1: 73%, Wave 2: 65%). High production of photographic works (82% <i>n</i> = 1, 69% <i>n</i> = 3 or more).	Photography instructions (“ <i>photo-missions</i> ”) and equipment unclear. Different outcome measures across waves. Intervention facilitated by primary researcher. Small sample size. Low completion rates of pre-post measures (reasons not provided). No demographic data. No control group.
Peterson (2015), USA	74	-		Hospital: Inpatient cancer-centre	Group	Digital photography and mindful outdoor walking, Collages constructed from photographs. Duration: 8 weeks Frequency: 2.5 hours, weekly. Number of photos required: - (10 selected for printing) Photographic equipment: Digital camera	Pre/post change scores on measures of psychological distress and health related quality of life in relation to demographics and illness burden (not specified).	Health benefits and improved self-regulation.	Outcome data not reported. Limited information regarding provision of digital camera. Demographic data absent. Attrition rates not reported. Group processes not controlled for. No control group. Potential for selection bias (recruited from cancer centre) No follow-up. Treatment not standardised.

Schudson (1975), USA	1	-	0	School: 7 th Grade	Individual	Photograph items of interest (write full-sentence caption for each photo). Film tokens earned via academic objective fulfilment. Duration: - (<1 school year) Frequency: - Photographic equipment: School camera and film roll.	Measure of self-concept (not specified)	Improved reading scores. Improved self-image, confidence and attitude towards school.	Minimal demographic information. Case study. Limited generalisability. Potential effects of peer support overlooked. Descriptive outcome data only. Limited methodological information.
Staiano, Baker & Calvert (2012), USA.	23	- 12 < 17	73.9	Summer School: Cafeteria	Individual	Photograph cafeteria food environment (“ <i>food/friends</i> ”) twice during lunch time. Duration: 4 weeks Frequency: Every lunchtime Number of photos: 2/lunch time Photographic equipment: Digital Camera.	Pre/Post: Weight, BMI, Physical health, waist:hip ratio.	Photographic fat content significantly predicted by waist:hip ratio: $F(1,21) = 4.602$, $p = .044$, $R^2 = 0.180$. Mean weight gain: 1.02kg ($n = 14$, 3 men, 11 women) predicted by nutritional values of photos. . Mean weight loss: 1.28kg ($n = 6$, 2 men, 4 women).	Limited to lunchtime food consumption. No control group. Second portions/disregarded food not accounted for. Absence of nutritional advice. Potential extraneous variables affecting adolescent food-choice overlooked. Limited generalisability.

Note: Dashes indicate data not provided in study

3.1 Missing data

Information regarding participants, interventions, photographic equipment, controls and outcomes were collated only where available. Assessment of reliability, validity and generalisability of findings was hindered somewhat by provision of limited information in many cases. This included limited participant information (Bradbury, Gross, Goodman & Straits, 2010; Davison, 2009; Land et al., 2009; Mizock, Russinova & DeCastro, 2015; Peterson, 2015; Schudson, 1975), limited information regarding photographic methodologies and equipment (Glover-Graf & Miller, 2006; Mizock et al., 2015) and omission of post-intervention outcomes in cases where outcome measures were implemented (Schudson, 1975; Peterson, 2015).

3.2 Participants

Sample sizes varied considerably from one (Schudson, 1975) to 74 participants (Peterson, 2015). Four studies included fewer than 10 participants. The remainder varied between 12 and 34. Sample sizes and demographic data were absent in three studies (Bradbury et al., 2010; Davison, 2009; Land et al., 2009). Attrition rates were reported in one case (Germain, 2004) citing loss of camera and “*difficult home circumstances*” as reasons. When reported ($n = 7$), participant age varied from aged 4 (DeMarie & Ethridge, 2006) to 70 years (Gregory, Walwyn, Bloor & Amin, 2005). Mean age of included participants across the studies based on available age data was 28.8 years, with the majority of studies including participants spanning pre-school to secondary school age ($n = 8$).

There was a higher proportion of females in all studies where gender was reported ($n = 7$), with the exception of Glover-Graf & Miller (2006), Schudson (1975) and Germain (2004) whose participants were predominantly male. The

mean percentage of females across the studies where details of gender were provided was 60.58%. Where health information was provided ($n = 7$), participants were patients attending an obesity/diabetic clinic (Gregory et al., 2015), patients considered to have “*serious mental illness*” (Mizock et al., 2015), adults with chemical dependence (Glover-Graf & Miller, 2006), individuals diagnosed with cancer (Peterson, 2015) and adults and adolescents with intellectual disabilities (Elinder, Brunosson, Bergstrom, Hagstromer & Patterson, 2012; Germain, 2004; Schudson, 1975). Studies were undertaken internationally including the USA ($n = 9$), UK ($n = 2$), Iceland (Einarsdottir, 2005) and Sweden (Elinder et al., 2012). Participant ethnicity was reported in one study only (Glover-Graf & Miller, 2012) in which participants were ‘*White*’ (20%) and Hispanic (80%).

In addition to formal therapeutic settings, participant-produced photography also featured in a number of related genres. These have been included in the review as they contain information regarding feasibility that is potentially relevant to the use of participant-produced photography in therapeutic settings for people with intellectual disabilities.

3.3 Genres

3.3.1. *Health/Wellbeing.* Three of the 13 identified studies described photography alongside supportive health/wellbeing interventions. These included a wellness-focused supportive oncology programme (Peterson, 2015); reflection on mental illness and identity (Mizock et al., 2015) and a present-focused approach for adults with chemical dependence (Glover-Graf & Miller, 2006).

3.3.2. Educational settings. Six studies took place within educational settings including pre-school/playschool ($n = 2$), primary school ($n = 4$) and a special educational needs school ($n = 1$). Across these settings, photography was incorporated with two primary aims: i) to enhance learning; ii) to facilitate information elicitation:

i) Learning enhancement. Three studies outlined the use of photography in schools to enhance learning. Schudson (1975) highlighted the utility of photography as an alternative channel of communication for a young person with an intellectual disability. Davison (2009) and Bradbury et al., (2010) used photography to enhance student learning based on exploration of specific concepts including science and the zoo. Positive outcomes were reported in all cases including improved academic performance and extension of learning experiences.

ii) Information elicitation. Three studies used photography to facilitate information elicitation from school children and young people with intellectual disabilities. Methods included a repeated measures design to evaluate comparisons of school day descriptions with and without photographs (DeMarie & Ethridge, 2006), comparisons between photographs taken by children using a digital camera under adult supervision versus unsupervised with a disposable camera (Einarsdottir, 2005) and photographs of extra-curricular social activities (Germain, 2004). In all cases, participant-produced photography supported communication and insight into life perspectives. However, conclusions made by authors must be interpreted cautiously, given the potential impact of methodological limitations including absence of control/comparison groups and participant heterogeneity.

3.3.3. Dietetics/Nutrition. Of the four studies investigating dietetics/nutrition, photography was used alongside traditional methods of dietary assessment (Elinder et al., 2012; Gregory et al., 2005), ordinary classroom nutritional concept learning (Land et al., 2009) and nutritional intake assessment in relation to paediatric obesity (Staiano et al., 2012). All studies pertaining to nutrition/dietetics reported findings from heterogeneous samples including '*low-income, African American adolescents*' (Staiano, Baker & Calvert, 2012), community-based adults with mild to moderate intellectual disabilities (Elinder et al., 2011), '*fifth grade*' school children (Land et al., 2009) and patients attending an obesity and diabetic clinic (Gregory et al., 2005).

3.4 Interventions

Interventions varied considerably. Duration ranged between one day ($n = 4$), three days ($n = 3$), one week ($n = 1$) and four to 12 weeks ($n = 4$). All single day interventions took place within school settings. Those spanning three days were associated with nutritional concepts, both in school and clinic settings. Interventions of longer duration (one week to 12 weeks) took place in inpatient, rehabilitation and hospital settings. Participants were provided with photographic equipment in six cases. Data regarding participant/camera ratios is limited; Davison et al. (2009) report that one digital camera was shared amongst a group of 5-6 students. Where reported, photographic equipment included disposable cameras ($n = 3$), pocket instamatic camera with a film of 12 exposures ($n = 1$) and "*school camera with roll of film*" ($n = 1$). Given considerable disparities amongst photographic interventions, alongside limited provision of methodological

information, prudence dictates that any inferences based on findings should be interpreted tentatively.

3.4.1. Use of *photographs*. Photographs were used in a variety of ways, including: the basis of a presentation to class-room peers (Bradbury et al., 2010), extension of otherwise ordinary learning experiences (Davison, 2009), a catalyst for descriptions of typical aspects of life (e.g. school day/extracurricular activities) (DeMarie et al., 2006; Einarsdottir, 2005; Germain, 2004), evaluation of inter-rater reliability between photographs and research observer (Elinder et al., 2012), comparison of self-reported energy intake based on food diaries alone versus food diary evidenced by photographs (Gregory et al. 2005), student ability to apply nutritional concepts (Land et al., 2009), as an integral aspect of a recovery narrative programme (Mizock et al., 2015), the basis of collages for mindfulness-based art therapy (Peterson, 2015), predictors of fat/caloric intake in relation to physical health changes (BMI, weights, waist-to-hip ratio) (Staiano, Baker & Calvert, 2012) and incentives for fulfilment of academic objectives (Schudson, 1975).

3.4.2. Instructions to participants. Methodological scrutiny in order to glean details of photographic interventions proved fruitful in all cases with the exception of Mizock et al. (2015) who described providing participants with “*photo-missions*” to elicit narratives based on “*Who I am,*” “*My story*” and “*My recovery*” (p.281). However, specific details regarding photographic equipment and instructions were unclear. In all other cases, participants received clear instructions regarding photographic expectations. Instructions included gathering photographic evidence of nutritional intake (Elinder et al., 2012; Gregory et al.,

2005; Land et al., 2009; Staiano, Baker & Calvert, 2012), educational concepts (Bradbury et al., 2010; Davison, 2009), exploration of experiential awareness (Peterson, 2015), items of interest (Germain, 2004; Schudson, 1974), environmental features deemed important (Einarsdottir, 2005) and photographs related to pre-selected weekly themes (trust, honesty, self-worth, power, healing and a self-portrait) (Glover-Graf & Miller, 2006).

3.4.3 Number of photographs required. Five studies stipulated the number of photographs required from participants. Peterson (2015) instructed participants to select ten photographs that they would like to be printed. Where specified, the number of photographs required ranged from one per eating/drinking occasion (Elinder et al., 2012; Gregory et al. 2005; Land et al., 2009), two per lunch time (Staiano, Baker & Calvert, 2012), four to five (Glover-Graf & Miller, 2006), and at least 10 (Davison, 2009). DeMarie and Ethridge (2006) provided participants with a film of 12 exposures. Where disposable cameras were provided, maximum number of photographs was determined by film roll capacity. In one case, tokens for more film-roll were contingent on fulfilment of academic objectives (Schudson, 1975).

3.4.4. Group vs. individual. Photography was undertaken as both group ($n = 6$) and individual activities ($n = 7$). Group approaches were implemented in school classroom settings ($n = 2$), outpatient clinic settings ($n = 2$) and inpatient hospital setting ($n = 1$). In the remainder of cases ($n = 6$), participant photography was a solo venture, with the exception of Einarsdottir (2005) whereby children took photographs either amongst peers (unsupervised) or with an adult chaperone (primary researcher). Positive outcomes were reported for both group and individual approaches. Given the potential for incidental positive outcomes of

group activities, including development of self-esteem, social skills, problem solving, decision making and leadership capabilities (Fidler, 1969; Mosey, 1973; Hunsburger, 1984), conclusions derived from group interventions should be interpreted cautiously.

3.4.4. *Involvement of others.* In most cases ($n = 11$), participants took photographs independently. In two cases involving people with intellectual disabilities, family/supporters played key roles (Elinder et al., 2012; Germain, 2004). Reminders to take photographs were required in 40% of all eating and drinking occasions for people with mild to moderate intellectual disabilities (Elinder et al., 2012). Parents of young people with intellectual disabilities played a key role in supporting camera use (Germain, 2004), and reported that participants took “*most*” of the photographs independently; photographs which subsequently facilitated transcendence of language barriers inherent within traditional didactic interviewing methods.

3.4.5 *Follow-up.* In all cases, interventions spanned the duration of the study only. There is a distinct absence of short or long-term follow-up to assess potential sustained improvements of factors such as psychological well-being or self-esteem across all studies appraised. Similarly, continued practise of photographic techniques following intervention completion remains unknown. As such, it is impossible to ascertain whether any improvements made were maintained; *or*, whether any potentially detrimental/positive findings were evident when participants were no longer required to take photographs. An awareness of such knowledge would inform the development of future interventions.

3.5 Control groups

Control groups are absent across all studies appraised. Between groups comparisons were made in one case (Einarsdottir, 2005). Findings indicated that disposable cameras were perceived as novel objects of play as indicated by the photographic content (e.g. peers *“having fun, doing something they should not be doing”* p.534) compared to more formal photographs taken by those using the digital camera. It is prudent to note that these findings may be mediated by adult supervision. Those using disposable cameras did so unsupervised, amongst a group of peers, for an unstipulated period of time (acknowledged by the authors as *“a longer time with the camera than the other group”* p.534). It is therefore impossible to ascertain whether the insightful content of the photographs produced by the children using a disposable camera was a result of potential extraneous variables such as the absence of adult supervision, longer duration of camera access/increased familiarity with the camera or simply individual differences (e.g. personal preference, confidence levels). Given the absence of control groups across included studies, it is impossible to decipher specific components attributable to successful interventions.

3.6 Outcome measures

Photographs taken by participants were key outcome indicators in all cases ($n = 13$). Additional systematic outcome measurement occurred in four studies, assessing self-esteem, trauma symptoms (Glover-Graf & Miller, 2006), psychological well-being, identity, empowerment (Mizock et al., 2015), psychological distress, health related quality of life (Peterson, 2015) and self-concept (Schudson, 1975). When reported, findings indicated increased self-

esteem ($+4.1 \leq +5.8$) (Glover-Graf & Miller, 2006) and visualisation of a more hopeful future (Mizock et al., 2015). Specific details of outcome measures used are absent in two cases (Schudson, 1975; Peterson, 2012).

In their assessment of meal quality and dietary diversity of people with mild to moderate intellectual disabilities, Elinder et al. (2012) relied on levels of inter-rater reliability of participant-produced photographs compared to observation by the researcher. Findings demonstrated excellent levels of correlation, indicating that photographs taken by participants with intellectual disabilities reliably depicted the focus of investigation. In three cases where outcome measures were collated, outcome data based specifically on the findings from outcome measures used were seemingly omitted; descriptive findings were provided instead. These included a participant commentary and a qualitative account of noted improvements (Peterson, 2015; Schudson, 1975). Mizock et al. (2015) found no significant differences on any of the measures administered, which they attributed to small sample size ($N = 16$) and missing data at post-test measurement, although reasons for this are not provided. In one case, results of systematic outcome evaluation were not reported (Davison, 2009). Mizock et al. (2015) implemented different outcome measures in Wave 1 and Wave 2, in order to “*better target outcome variables*” (p. 281). Completion of pre/post outcome measures in Wave 2 was low. The reasons for this were not provided. Furthermore, where systematic evaluation was reportedly undertaken (Davison, 2009), results were not reported. Provision of such information may have proven pivotal to informing/underpinning methodological rigour of future research.

3.7 Effects of photography on outcomes

On the basis of the studies appraised, the authors made a number of claims suggesting that photography facilitated an array of powerful effects, including:

- A context for ordinary activity to become a powerful tool for construction of meaning (Davison, 2009);
- Information gleaned from questioning alone doubled with inclusion of photographs (more detail provided, improved recall and verbal ability) (DeMarie & Ethrdige, 2006);
- Transcendence of language barriers (Germain, 2004);
- Improved self-esteem and sense of empowerment (Glover-Graf & Miller, 2006; Schudson, 1975; Germain, 2004; Mizock et al., 2015);
- Increasingly accurate representation of participant descriptions (Gregory et al., 2005; Land et al., 2009);
- Enhanced learning, sense of inquisitiveness and wonder (Davison, 2009; Bradbury et al., 2010; Land et al., 2009; Schudson, 1975);
- A memory prompt for prior actions (Land et al., 2009)
- Energised participants and increased levels of focused attention on the surrounding environment (Bradbury et al., 2010);
- Improved communication and description of activities (DeMarie & Ethridge, 2006).
- Enabled initial responses to be non-verbal, providing participants with a tangible object from which to speak (Glover-Graf & Miller, 2006).
- An effective tool in promoting personal development and growth (Schudson, 1975).

However, as has been outlined above, there are sufficient methodological limitations in the papers cited to require caution in accepting these ‘findings’ without further replication.

4. Discussion

The current narrative review investigated participant-produced photography across a range of specialisms in order to assess feasibility and extrapolate meaningful abstractions regarding implementation for people with intellectual disabilities. Based on the claims made by authors of the studies appraised, participant-produced photography appears to show considerable promise as an integral aspect of therapeutic approaches. In the absence of conclusive findings indicating the most efficacious photographic approaches and for whom, the underlying mechanisms of purportedly ‘*effective*’ interventions remain unclear. However, supporter presence has been indicated as helpful for participant-produced photography interventions for people with intellectual disabilities (Elinder et al., 2012; Germain, 2004).

4.1 Limitations. Literature on participatory visual methods has been critiqued in the past for being overly descriptive (Drew & Guillemin, 2014). As such, the findings of the current narrative review should be considered in terms of both methodological limitations of included studies and the review itself. Despite promising findings, studies included within the current review are underpinned by methodological limitations which render inference of findings beyond the study almost impossible. Sample sizes were relatively small, with the exception of Peterson (2015) whose sample size ($N = 74$) is representative of a cumulative sample who participated over a number of years.

As has been outlined above, conclusions based on studies with considerable methodological limitations including small sample sizes, limited provision of demographic data and absence of comparison or control groups should be interpreted with extreme caution. These limitations will now be discussed in more detail.

As with any review, the potential for publication bias towards successful interventions must also be borne in mind. Furthermore, in the absence of follow-up data, it is impossible to ascertain whether positive outcomes were maintained. As with all methods of self-monitoring, participation was dependent on participant motivation to provide complete, non-selective accounts. Whilst photography potentially enables self-expression, possible unanticipated, contradictory consequences have been highlighted by Prins (2010). These include photography's simultaneous ability to generate suspicion, embarrassment and shame. Participant honesty may be mediated by perceived shame or anticipated treatment consequences. This is of particular relevance in healthcare settings, where future service provision may be perceived as dependent on '*photographic performance*.' High rates of refusal to participate noted by Germain (2004) may have been influenced by perceived surveillance.

In some cases, precise detail regarding type of photographic equipment, its use and instructions to participants were unclear ($n = 5$). For example, in studies pertaining to nutritional concepts ($n = 4$), the need to record food not consumed ('*plate-waste*') or to take additional photographs to capture surplus amounts was not stipulated. Further information regarding camera provision would serve to inform findings, highlighting the potential impact of extraneous variables, such as peer support/group processes.

Potentially confounding variables such as neuropsychiatric co-morbidities and psycho-pharmacological treatment were not controlled for amongst appraised studies. Inclusion of studies from Western societies restricts the extent to which the findings may be applicable to wider cultural contexts. Of further relevance is the exclusion of random assignment. Where recruitment methods were stated, random selection was the exception (Staiano et al., 2012), in which participants were “*randomly selected from a college-preparatory programme on a university campus,*” (p.699). Absence of random selection in the majority of included studies raises the issue of potential selection bias, including recruitment from clinic and school settings. As such, the potential for coercion and factors underpinning motivation to participate should be borne in mind (e.g. progress through care-pathways/academic achievement). Similarly, some findings such as increased self-esteem and provision of detailed information when discussing photographic content may have been influenced by prior familiarity with peers (Glover-Graf-Miller, 2006) or ‘co-researchers’ (“*familiar adult*”/pre-school teachers) who asked participants to talk about the photographs they had taken (DeMarie & Ethridge, 2006; Einarsdottir, 2005).

4.2 Future Research. Service-user led photography carries sufficient promise to warrant further research into its therapeutic effectiveness (Graf, 2002). In order to enhance understanding of successful intervention components, future research requires rigorous methodological approaches to systematically evaluate incorporation of service-user produced photography within therapeutic settings for people with intellectual disabilities, over a substantial period of time. This would require an awareness of potential practical challenges that should not be overlooked (Stewart, 1979; Germain, 2004; Switzer et al., 2015). These include:

- Provision/maintenance of equipment (and cost implications);
- Potential technical glitches/loss of camera/failure to return camera;
- Potential loss of photographs/difficulty re-capturing lost data;
- Issues associated with camera use (e.g. reading ability/vision, dexterity);
- Photographic content/issues of confidentiality, vulnerability, anonymity and stigma.

Methodological insights reinforce the importance of attending to the entire process of engagement with photography when working alongside people with intellectual disabilities, inclusive of the act of taking photographs, consideration of systemic issues/home circumstances and exploration of service-user views of taking photographs prior to participation in preparation for potential criticisms (Prins, 2010). Transparent documentation of the process of selection, implementation and modification of methodological decisions would enhance development of evidence that may be comprehensively evaluated for its rigour, potentially expanding the possibilities of using participant-produced photographic methods in a range of settings and contexts (Switzer et al., 2015).

Technological advances and personal, photography-enabled technology such as mobile phones, tablets and inexpensive digital cameras potentially alleviate cost implications by eliminating the need to provide participants with cameras. However, the ethical and clinical governance issues associated with utilisation of personal photographic equipment (particularly within healthcare settings and clinical populations) should be considered carefully, mindful of the potential challenges outlined above. Future research may navigate potential dilemmas by ensuring careful service-user selection based on comprehensive

assessment of individual and systemic circumstances, in conjunction with multi-disciplinary colleagues, tailoring approaches to suit individual circumstances. Further development of participant-produced photographic interventions for people with intellectual disabilities should explore the mechanisms underlying effective implementation, embracing the spirit of meaningful co-production and incorporate systematic outcome measurement using psychometric tools valid for use with people with intellectual disabilities.

4.3 Clinical Implications. As clinicians, interpretation and implementation of conclusions derived from the evidence appraised within the current paper is of utmost importance. One of the most pertinent findings is the heterogeneity of current evidence. As with any novel approach, professional practice must be underpinned by a sound evidence base, mindful of both clinical knowledge and evidence from existing research. Participant-produced photography using digital or disposable cameras may potentially be directly applied to clinical practice, with implied benefits of improving access to, and engagement with, psychological therapies for people with intellectual disabilities.

Although implementation of participant-produced photography within services may prove costly in the short-term, service provision and meaningful engagement with psychological therapy and its subsequent potential impact on relapse/rates of re-referral for therapeutic input may be profoundly affected in the future. Experienced clinicians may work alongside service-users, supporters and wider networks to consider flexibly tailoring existing therapeutic approaches to incorporate service-user led photography. Whilst remaining mindful of potential challenges, professionals should ensure multi-disciplinary commitment from the

outset, considering wider team and service provider perspectives to address potential cost and treatment implications.

4.4 Summary/Conclusions. Although in its infancy, existing evidence for participant-produced photography holds promise for its potential incorporation into therapeutic settings for people with intellectual disabilities. Considerable methodological limitations are apparent across existing research including small sample sizes, lack of comparison/control groups and follow-up data. In some cases, it is difficult to decipher whether promising findings are underpinned by photography itself, talking about photographs, or the notion of increased surveillance and/or incidental effects of group processes/increased attention.

Given the heterogeneity of studies, measured outcomes, participants and photographic interventions, development of a conclusive theory regarding the use of participant-produced photography for people with intellectual disabilities has proven challenging. However, the feasibility of participant-produced photography has been indicated across a range of individuals, including those with intellectual disabilities. Encouragingly, results suggest that programmes using inexpensive, simple photographic equipment, combined with targeted discussion of photographs can facilitate a shift from ‘learner’ to ‘expert’ status in the therapy room. This can facilitate a sense of value, empowerment and improved self-esteem. Participant-produced photography within the therapeutic space has the potential to transcend language barriers, enhance memory recall and increase focus on valued aspects of life, encouraging reflection on experiences, whilst highlighting discrepancies between photographic content and personal beliefs (Land et al., 2009; Elinder et al., 2012; Cargo, Grams, Ottoson, Ward & Green, 2003).

Further investigation embracing systematic assessment of meaningful outcome measures, controlled investigation and clear, coherent photographic interventions is required. In order to examine the feasibility of participant-produced photographic approaches for people with intellectual disabilities, research methodologies such as multiple baseline single case design have the potential to gather rich data based on small numbers of participants. Such methodologies may be particularly suitable for preliminary research ventures, in order to systematically evaluate feasibility. In the future, comparative longitudinal studies examining the effects of participant-produced photography incorporated into therapeutic settings would be particularly valuable to determine the stability of treatment effects (Graf, 2002).

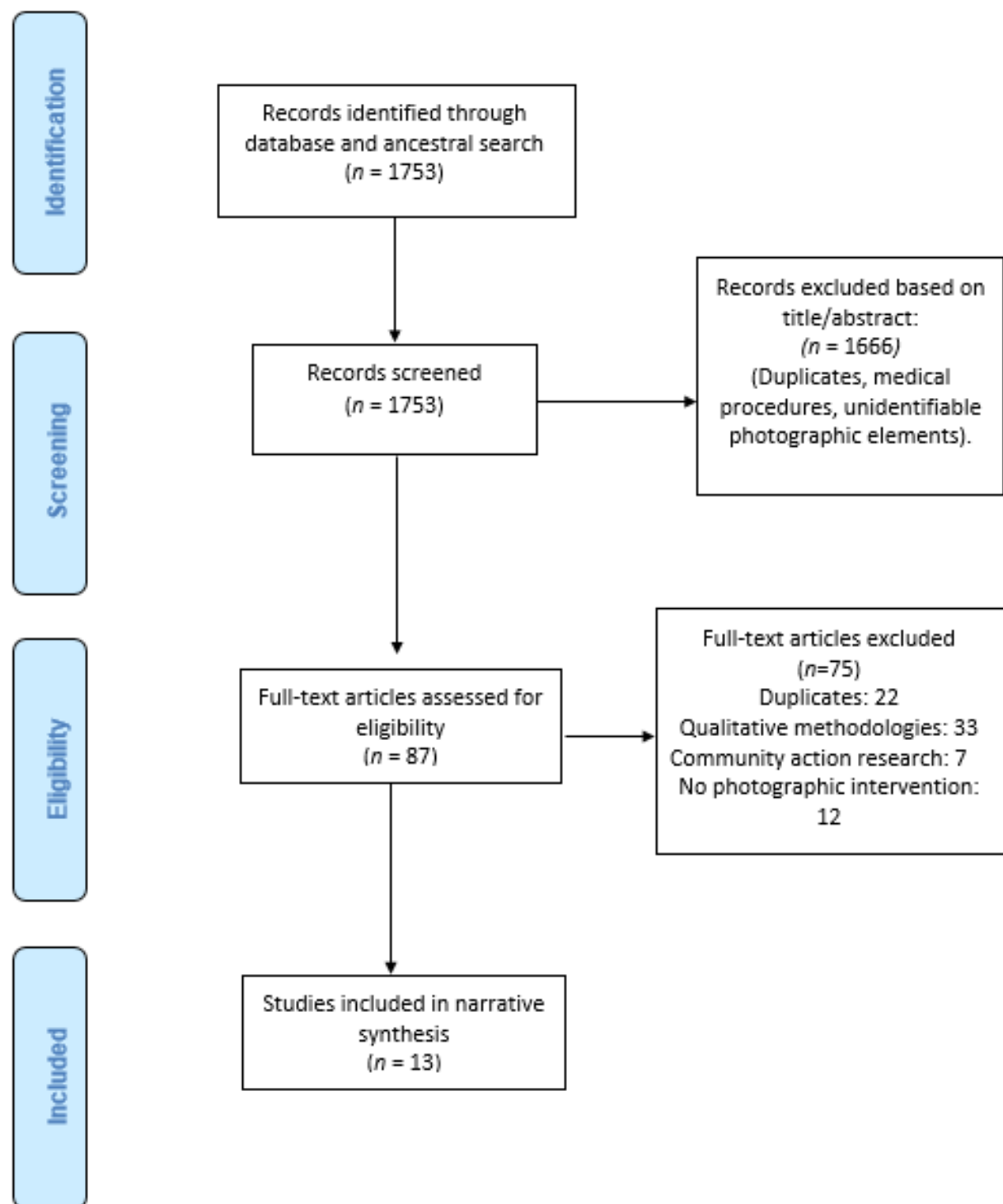


Figure 1. PRISMA Flow diagram of study selection process

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Chapter 2 – Empirical Paper

Catching What Matters: A value-based intervention for people with intellectual disabilities²

² This chapter formed the basis of a paper submitted to the Journal of Applied Research in Intellectual Disabilities (Boulton, Williams & Jones). Catching What Matters: a value-based intervention for people with intellectual disabilities. Journal submission guidelines are contained at the start of this chapter.

Journal of Applied Research in Intellectual Disabilities: Author Guidelines



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1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

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Catching What Matters: A value-based intervention for people with intellectual
disabilities

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Abstract

Background: There is limited evidence regarding clinical effectiveness of therapeutic interventions for people with intellectual disabilities (ID).

Developments in psychological therapies have led to a modern generation of therapies, including Acceptance and Commitment Therapy (ACT). Previous research has highlighted challenges regarding adaptation of ACT for people with ID.

Method: A component-analysis was undertaken, focusing on ‘values,’ augmented by participant-produced photography. A multiple baseline design across participants was implemented. Self-reported ratings of anxiety, mood, experiential avoidance and life satisfaction were collated via text message every three days.

Results: Visual inspection of findings suggested minimal effectiveness of a value-based approach in isolation. Photography facilitated clarification of the concept of values.

Conclusions: Value-based intervention may be *necessary*, but not *sufficient* for therapeutic change. However, the data are suggestive of relationships that warrant further scrutiny. The study lends support to the use of text based data collection for intervention research with people with ID.

Key words: ACT, intellectual disability, participant-produced photography, multiple-baseline.

Catching What Matters: A value-based intervention for people with intellectual disabilities

Introduction

Higher prevalence rates of mental health difficulties are widely reported amongst people with intellectual disabilities in comparison to the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Osugo & Cooper, 2016). Despite this, robust empirical evidence regarding the clinical effectiveness of therapeutic interventions for people with intellectual disabilities remains limited (Osugo & Cooper, 2016).

Traditionally, therapeutic interventions have incorporated didactic assessment and intervention methods, which some have argued to be the most appropriate means of gathering information (Erdner & Magnusson, 2011). Communication/conceptual issues associated with intellectual disabilities may affect meaningful engagement with traditional therapeutic approaches and articulation of life experiences in this way (Chinn et al., 2014). To overcome these problems, emerging evidence suggests that modification of standard psychological interventions may enhance accessibility of mainstream approaches for people with intellectual disabilities (Osugo & Cooper, 2016).

Recent developments in psychological therapy have led to the emergence of a modern generation of behavioural therapies, including Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999; Hayes, Kirk, Strosahl & Wilson, 2011), Dialectical Behaviour Therapy (Linehan, 1993) and Compassion Focused Therapy (Gilbert, 2009). ACT's overarching ethos is promotion of psychological flexibility and the need to embrace necessary suffering/foster acceptance in order to increase commitment to valued living (Hayes, Pistorello & Levin., 2012; Harley, 2015; Gore & Hastings, 2016). Values, a core concept of ACT, are considered as self-identified verbal constructs that confer reinforcing properties on particular behaviours in line with those

values (Hayes, Villatte, Levin & Hildebrandt, 2011). This is an abstract concept which may be difficult for some people with intellectual disabilities to grasp.

Despite a well-established evidence base for ACT in the general population (e.g. Ost, 2014), literature for adults with intellectual disabilities is sparse (Harper, Webb & Rayner, 2013; Leoni, Serafino, Cavagnola, 2015; Gore & Hastings, 2016). Pankey and Hayes (2003) reported promising findings from a four-session adapted ACT intervention for the treatment of psychosis, noting particular improvements in self-reported levels of distress for a female with intellectual disabilities. The effectiveness of a brief group intervention for people with intellectual disabilities based on ACT has been demonstrated by Pankey and Hayes (2008), who reported findings including increased psychological flexibility, time spent focused on important values and valued living. Pankey and Hayes (2008) make the important point that whereas ACT relies on metaphorical language in an effort to expand or extend behavioural repertoires, people with intellectual disability “*can often present with very limited abilities to reason beyond a very concrete and linear understanding of thoughts and events*” (Pankey & Hayes, 2008 p. 29).

A later study by Brown and Hooper (2009) reported an adapted ACT intervention for the management of anxious, obsessive thoughts for a young person with moderate to severe intellectual disabilities. These authors also reported the challenges of facilitating development of a sound understanding of the concept of ‘values.’

A promising direction to evaluate the effectiveness of therapeutic strategies that may be meaningfully accessed by people with intellectual disabilities is to undertake a component analysis of the therapeutic ‘package’ to determine what aspects or components of that package are amenable to adaptation.

ACT is a promising candidate for component analysis due to its modular nature. Component analyses enable maintenance of evidence base links, whilst facilitating selection of elements suitable for feasibility evaluation within practice settings

(Rotheram-Borus, Swendeman, & Becker, 2014). Six core components of ACT are typically reported in the literature (see Hayes et al., 2011). These are Acceptance; Cognitive Fusion; Being Present; Self as Context; Values and Committed Action.

Given the findings of Pankey and Hayes (2003; 2008) and Brown and Hooper (2009), a component analysis study, focusing specifically on the values component, represents a logical avenue for further exploration. It seems clear that an understanding of values is *necessary* for someone with intellectual disabilities to benefit from an ACT intervention. Whether an understanding of values is *sufficient* for therapeutic benefit is an empirical question. Although it is unlikely that a single component will have a therapeutic effect alone, without concurrent adaptation of the other identified components, the individual testing of the effectiveness of individual components is an important procedural step in any component analysis. This allows for the eventual identification of the active components of any therapeutic package.

Feasibility and effectiveness of treatment modules targeting specific, individual components of ACT within the general population have been reported by Villatte et al., (2016), indicating a 73% improvement in values-based behaviour, sustained quality of life improvements, and high levels of treatment satisfaction. At the same time, difficulties in facilitating full engagement in values work amongst individuals in the general population have been noted by Wilson and Murrell (2004).

The challenge for the current investigation was, therefore, to explore a method of making the concept of values more accessible to people with intellectual disability despite a possible “*concrete and linear understanding of thoughts and events*” (Pankey & Hayes, 2003 p. 29). Research within the general population has suggested that future ACT-based research endeavours embrace creative methodologies (Orsillo, Roemer, Lerner & Tull, 2004). To this end, participant-produced photography was chosen as a potential mechanism.

Photographs represent powerful tools, able to convey action and emotions, capturing life events often unreachable through language alone (Enzman-Hagedorn, 1996). Given that ACT provides a natural context for the exploration of the sense made by individuals of existence and life purposes (Steger et al., 2013), participant-produced photography (taking photographs of valued aspects of life) represents a potentially feasible way in which the concept of values may be understood by people with intellectual disabilities. Such technique may encourage objectivity and facilitate focus on positive environmental features (Borkovec & Sharpless, 2004).

The current feasibility study undertook a component-analysis investigation, focusing specifically on the ‘values’ concept of the ACT model. In order to enhance accessibility of this abstract concept for people with intellectual disabilities, the concept of values was augmented by participant-produced photography. A multiple baseline design across participants was implemented to simultaneously collate self-reported ratings of anxiety, mood, experiential avoidance and life satisfaction via text message to monitor progress throughout. To the authors’ knowledge, this novel approach is the first of its kind in the intellectual disabilities literature.

Method

Participants

Participants were eligible for inclusion based on the following criteria:

1. Previously diagnosed intellectual disability
2. Aged 18+
3. Clinically significant levels of anxiety (score of 13+ on Glasgow Anxiety Scale-Intellectual Disability, Mindham & Espie, 2003).
4. Capacity to provide informed consent
5. Basic familiarity with the process of taking photographs and sending/receiving text messages.

Participants were excluded based on the presence of:

1. Active psychosis/mania, suicidality or serious self-harm behaviour
2. Lack of capacity/non-consent to commitment that participation would involve.

Sixteen participants were identified as potentially suitable. Wider systemic factors including exacerbation of ongoing mental/physical health issues between the point of referral and pre-intervention data collection subsequently rendered eight unsuitable for assessment. Of the remaining eight, one was deemed to lack the capacity to provide informed consent and one withdrew consent following three weeks of baseline data collection citing the perceived burden of responding to text messages in addition to existing demands. The remaining six completed all phases of the study.

Participants were four males and two females with a mean age of 32.33 years ($SD = 22$ years). All had a documented history of anxiety and mild intellectual disabilities.

Ethical Considerations

The study received NHS and University ethical approval and participants were recruited from National Health Service Community Learning Disabilities teams. A functional assessment of capacity to consent (Arscott, Dagnan & Kroese, 1998) was undertaken for all participants and their right to withdraw consent at any time was outlined. Written informed consent was obtained from each participant. Limits of confidentiality were outlined initially by the primary researcher and reiterated by trial therapists at the start of the intervention (see Appendices A-K & U).

Procedure

Participants completed preliminary psychometric assessments at their chosen location (participant's home, $n = 5$; day service, $n = 1$). During pre-baseline visits, participants practised using the mobile phones, taking photographs and responding to text

messages. With permission from participants, supporters (paid support staff/family members) were involved from the outset (Elinder, Brunosson, Bergstrom, Hagstromer & Patterson, 2012).

Materials

Mobile phone. Participants were provided with an internet disabled pay-as-you-go mobile phone (Nokia 108) registered to the research team including £20 phone credit (see Appendix Q). All participants agreed to adhere to pre-determined limits regarding phone use (e.g. use for research purposes only).

Automated Text Message Service. Data was collected every three days via text messages scheduled in advance, sent through FireText (an online automated text messaging service). Participant replies rating self-reported levels of mood, anxiety, experiential avoidance and life satisfaction were collated via FireText anonymously in numerical format (See Appendices O, P, R & S).

“Catching What Matters” Intervention Manual (See Appendix T). A therapy manual was constructed to ensure consistency across therapists. This outlined the background to the study and detailed the content of the 6 sessions provided. The focus of the manual was to enable participants to understand the concept of core-values and to focus on how a values-based intervention may be helpful.

Study design

A multiple baseline across participants design was used (Barlow, Nock & Hersen, 2009). The design had three phases: i) baseline ii) intervention and iii) follow-up. Data from three pairs of participants are reported where each pair was yoked using the multiple baseline design.

1. ***Baseline.*** This phase was used to establish baseline levels of mood, anxiety, life satisfaction and experiential avoidance assessed by responses to text messages

sent every three days. Participants and supporters were instructed to continue with everyday life and activities as usual. Baseline data was collected for a minimum of two weeks, prior to awaiting stability (at least three stable data points).

2. ***“Catching What Matters” values-based intervention:*** Upon attainment of baseline stability, the first participant of each dyad entered the intervention phase. Participants were contacted by the primary researcher and instructed to begin to take photos of valued aspects of life, whilst continuing to respond to text messages every three days rating self-reported levels of mood, anxiety, experiential avoidance and life satisfaction. At a convenient time and location, participants met with an experienced psychology clinician for six sessions to undertake *Catching What Matters*, a six session manualised values-based intervention on a one-to-one basis. Each session lasted between 30 minutes and an hour.
3. ***Follow-up.*** Following completion of the intervention phase, participants continued to respond to text messages rating self-reported levels of mood, anxiety, life satisfaction and experiential avoidance for two weeks to assess the durability of treatment gains. No experimental variables were manipulated during follow up and participants were instructed to refrain from taking photographs.

Therapists

Catching What Matters was provided by three clinicians (a Trainee Clinical Psychologist, a Senior Clinical Psychologist and a Consultant Clinical Psychologist). All therapists had extensive experience of values-based psychological interventions as well as clinical expertise and experience in service delivery to individual with intellectual disabilities. Therapists followed the treatment manual and were deliberately blinded to the results of the baseline assessments and text-based ratings that were provided directly to the researcher.

Data Collection

Data were collected via FireText every three days. Replies were collated for the following ratings:

1. **Anxiety:** “How worried are you today?” 1) “no worries,” 2) “not very worried,” 3) “in the middle,” 4) “a fair bit worried,” 5) “very worried;”
2. **Experiential avoidance:** “How scared are you to do the things you want to do?” 1) “not scared at all” 2) “not very scared,” 3) “in the middle” 4) “a fair bit scared,” 5) “very scared.”
3. **Mood:** “How happy are you today?” 1) “not happy at all,” 2) “not very happy,” 3) “in the middle,” 4) “a fair bit happy,” 5) “very happy;”
4. **Life Satisfaction:** “Do you like your life today?” 1) “my life is rubbish,” 2) “I don’t like my life very much,” 3) “in the middle,” 4) “I like my life a fair bit,” 5) “I love my life.”

Self-report ratings were facilitated by ‘easy-read’ rating-scales provided in laminated A4, wallet sized and key ring sized versions.

Outcome Measures

Levels of anxiety and depression (pre and post-intervention) and retrospective significant life events were captured using self-report and informant based questionnaires suitable for use with people with intellectual disabilities (see Appendices L-N).

Self-Report Measures

Anxiety. Anxiety was assessed using the Glasgow Anxiety Scale-Intellectual Disability (GAS-ID; Mindham & Espie, 2003). The GAS-ID is a 27-item instrument assessing self-reported levels of anxiety using a “never/sometimes/always” scale. A total score (range = 0 – 54) was obtained by summing the total items endorsed by participants. Higher scores indicated greater symptomology. The GAS-ID has good test-retest

reliability ($r = 0.953$; $p < 0.0001$, two-tailed) and internal consistency (Cronbach's $\alpha = 0.96$), offering a psychometrically robust and practical (five to ten minute) approach to appraisal of anxiety for people with intellectual disabilities.

Mood. Self and informant-rated levels of depression were assessed using the Glasgow Depression Scale for people with a Learning Disability (GDS-LD, GDS-CS; Cuthill, Espie & Cooper, 2003). The GDS-LD is a 20-item depressive-symptom rating scale for assisted self-completion by individuals with mild to moderate intellectual disabilities. “*A present state tool*” (Cuthill, Espie & Cooper, p.350), the GDS-LD gauges symptom levels over a one week period. The GDS-LD has good test-retest reliability ($r = 0.97$) and internal consistency (Cronbach's $\alpha = 0.90$). Participants were required to indicate the frequency (“*never/no, sometimes, always/a lot*”) of common indicators of depression. A score was subsequently derived by summing the 20 items (range 0 - 40). Higher scores indicated greater depression symptomology.

Life Events. Given the potential impact of life events during participation (Wigham, Taylor & Hatton, 2014), significant life events during the period of research participation were retrospectively assessed using the Bangor Life Events Schedule for Intellectual Disabilities – Self Report (BLESID-SR; Hulbert-Williams, Hastings, Crowe & Pemberton, 2013). The BLESID comprises 24-items and assesses exposure to life events (such as bereavement, moving house, changing jobs), rating their frequency and impact from negative to positive.

Informant measures

Mood. The Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability (GDS-CS) is a 16-item assessment of depression based on direct carer observation. The GDS-CS has good test-retest reliability ($r = 0.98$) and internal consistency (Cronbach's $\alpha = 0.88$).

Life Events: The informant version of the Bangor Life Events Scale for Intellectual Disabilities (BLESID; Hulbert-Williams et al., 2013) has 38 items rated on a 3-point frequency scale, and a 5-point impact scale. Individual item scores are calculated by multiplying the frequency of negatively rated life events by their impact.

Data Analysis

The multiple-baseline data was assessed through visual inspection of the plotted graph. Percentage of non-overlapping data (PND; Scruggs, Mastropieri & Casto, 1987) analysis was undertaken to facilitate further data exploration. This enabled calculation of the percentage of intervention phase data points exceeding the single greatest baseline phase value (Parker, Vannest & Davis, 2011). A score of < 50% indicates no observed effect (Scruggs & Mastropieri, 1998).

Statistical analyses were performed using SPSS version 22. *Reliable Change Index* (RCI) was calculated in order to evaluate individual improvement scores for the GDS-LD. Qualitative information gleaned from the BLESID was used to inform understanding of the potential impact of significant life events.

Results

Six participants completed all phases. Self-reported levels of anxiety, experiential avoidance, mood and life satisfaction collated via text message during baseline, intervention and follow-up are presented in Figures 1 to 4. Phase means for each variable are presented within the graphs and numerically in Table 1.

Insert Table 1 here

Anxiety

Visual inspection of the multiple baseline graph did not indicate clinical effectiveness. Decreases in mean self-reported ratings of anxiety during the course of the intervention were apparent for John (pseudonyms are used throughout), Wayne and Ryan, which were maintained at follow-up. Rose-Anna's self-reported rating of anxiety increased during the course of the intervention and follow-up; Lionel's mean self-reported anxiety score fluctuated between phases and was lower than baseline at follow-up.

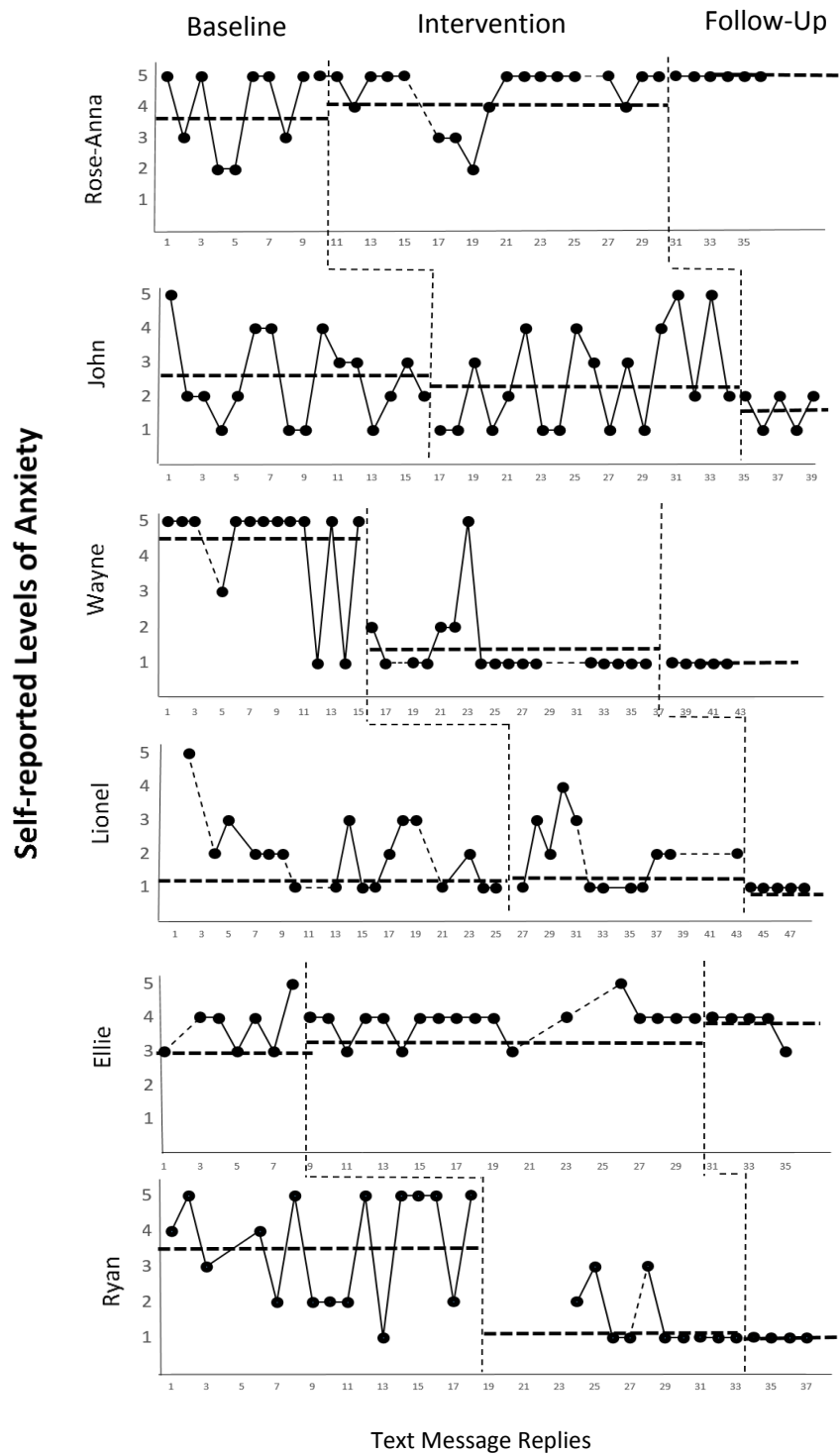


Figure 1. Self-reported rating of anxiety collated every three days in response to the question “how worried are you today?” (1 = “no worries at all,” 5 = “very worried”).

Experiential Avoidance

Visual inspection of the multiple baseline graph did not indicate clinical effectiveness. Mean self-reported levels of experiential avoidance decreased in the cases of John, Wayne, Lionel and Ryan. For Rose-Anna and Ellie, self-reported ratings of experiential avoidance increased during intervention and follow-up.

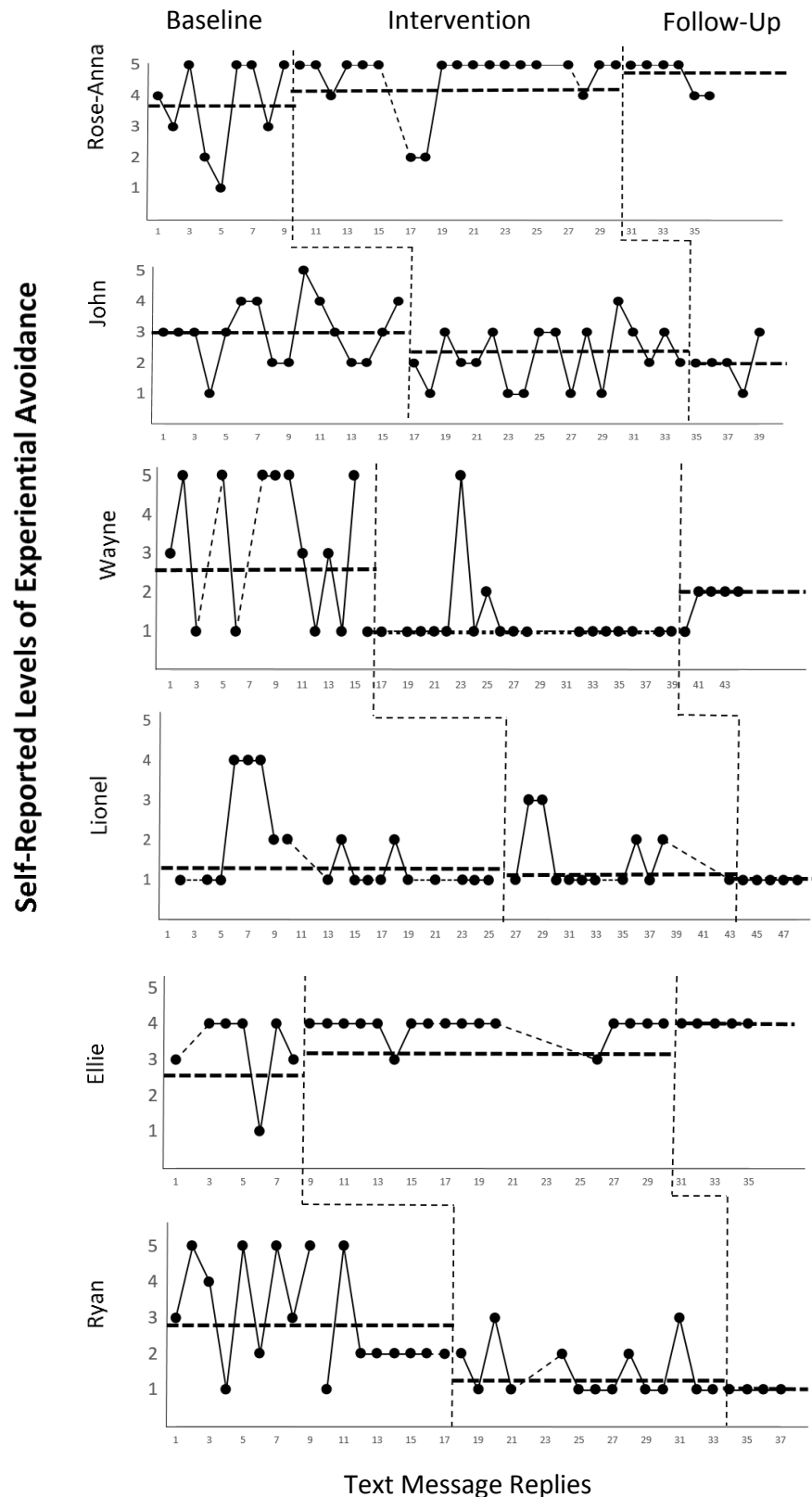


Figure 2. Self-reported rating of experiential avoidance collated every three days in response to the question “*How scared are you to do the things you want to do?*” (1 = “very scared,” 5 = “not scared at all”).

Mood

Visual inspection did not indicate clinical effectiveness. With the exception of Rose-Anna and Lionel, participants indicated increased perception of happiness whilst taking photographs of valued aspects of their lives and talking about them with therapists. Both Rose-Anna and Lionel's self-reported mood s decreased during the intervention phase and subsequently increased to levels greater than baseline at follow-up.

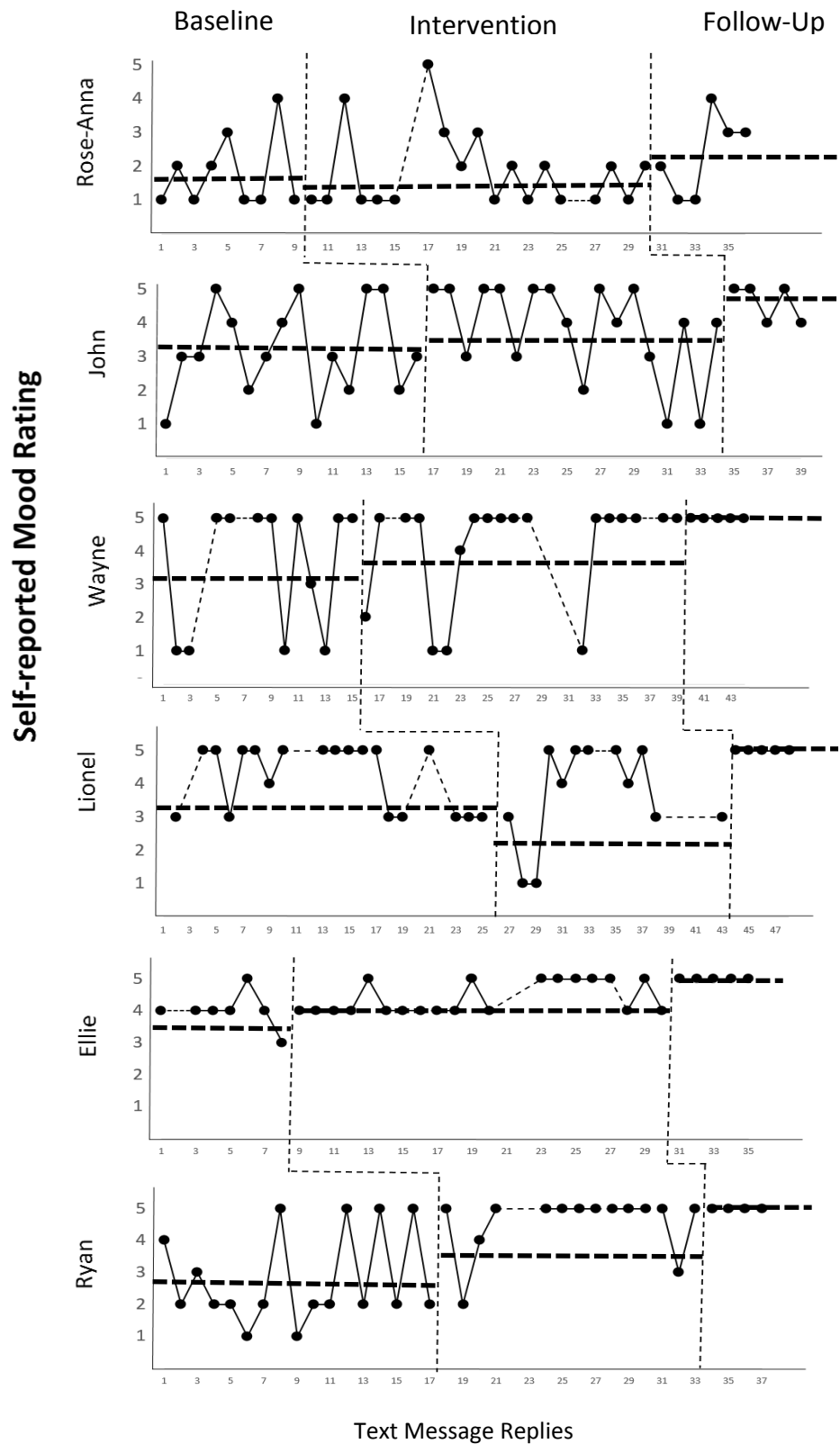


Figure 3. Self-reported rating of mood collated every three days in response to the question “How happy are you today?” (1 = “not happy at all,” 5 = “very happy”).

Life Satisfaction

Clinical effectiveness was not apparent through visual inspection. Phase mean increases in life satisfaction scores from baseline to follow-up are indicated for all participants. In Lionel's case, levels of self-reported life satisfaction decreased during the intervention phase and subsequently increased at follow-up to a level greater than baseline.

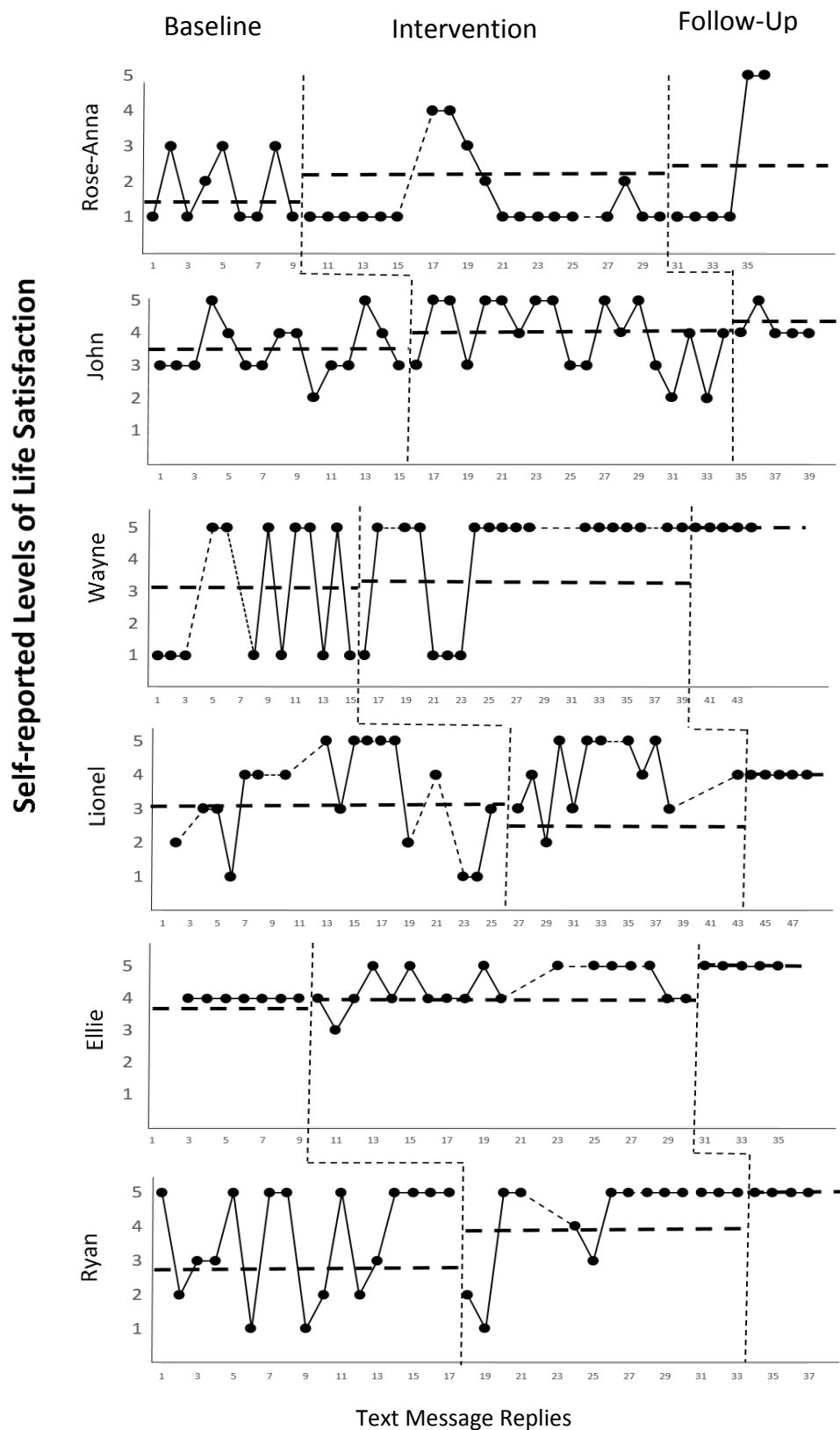


Figure 4. Self-reported rating of life satisfaction collated every three days in response to the question “Do you like your life today?” (1 = “my life is rubbish,” 5 = “I love my life”).

Further Data Analysis

Absence of clinical effectiveness was confirmed by a PND score of 0% in all cases with three exceptions: Rose-Anna's self-reported rating of mood (PND = 1/19, 5.27%) and life satisfaction (PND = 2/19, 10.53%) and Ellie's self-reported life-satisfaction ratings (PND = 8/18, 44.4%).

Outcome Measures

Pre and post-intervention outcome scores for all participants are outlined in Table 2. Outcome measure Mean (*M*) and Standard Deviation (*SD*) values are presented in Table 3.

Insert Tables 2 and 3 here

Some common themes were apparent across participants based on self-report and informant versions of the BLESID. These included '*happened once/more than once*' responses to the following items: "*permanent change in staffing*" (*n* = 3), "*death of close friend/relative*" (*n* = 3), "*subjected to verbal abuse*" (*n* = 4) and "*break up of friendship*" (*n* = 2), all of which were rated as having a negative impact. "*Permanent change in staffing*" was noted by four participants (including all of those living in staff-supported residential settings (*n* = 3), and received a mixture of both '*positive*' and '*negative*' impact ratings.

Individual Change

Individual improvement scores were calculated to enable analysis at an individual level. By subtracting pre-test scores from post-test scores for each participant, individual improvement scores were obtained. The *Reliable Change Index* (RCI) is a measure of clinical significance. The RCI enables analysis of the effect of an intervention on individuals (Jacobson & Truax, 1991; Zahra & Hedge, 2010). Using the RCI, individual improvement scores were used to determine how many participants demonstrated reliable change at post-test. Reliable change scores are calculated by:

- Calculation of the difference scores (post-test minus pre-test scores) for each participant
- Dividing the difference score by the standard error of the differences.

If the difference is greater than 1.96 times the standard error (equivalent of the 95% confidence interval), the chances of change due to measurement of variability are greatly reduced. As such, the difference scores for participants attaining or surpassing this reliable change score reliably indicate improvement in performance. Clinically Significant Change (CSC; Jacobson & Truax, 1991) was calculated in to further examine whether any changes were clinically significant.

RCI was not calculated for the BLESID/BLESID-SR due to the retrospective nature of the measure (i.e. no pre-test measurement). Available psychometric properties of the outcome measures used rendered it possible to calculate RCI for the GDS-LD, which provided a standard deviation score ($SD = 6.30$) for the ‘depressed’ group (score of 13 or above). Data required to calculate RCI for the GAS-ID and GDS-CS was unavailable, therefore was unable to be calculated.

John, Wayne, Ellie and Ryan indicated reliable change at post-test. All pre/post-test changes were clinically significant, with the exception of John. The results are outlined in Table 4.

Feasibility Data

In order to explore feasibility of the novel approach for people with intellectual disabilities, the number of photos taken between sessions and the number of sessions with the *Catching What Matters* therapist were recorded. The results can be seen in Table 5. Frequency of text message replies was also collated. Where text message replies are missing, dashed lines are indicated within Figures 1 to 4.

Insert Table 5 here

With the exception of Ellie, participants attended all sessions offered. Ellie had forgotten that the session was due to take place and gone shopping with family, an activity which she had previously reported as anxiety provoking.

Discussion

The aim of the present research was to undertake a component-analysis study to evaluate the feasibility of adapting a value-based intervention for people with intellectual disabilities. These initial findings suggested that, while value-based intervention may be necessary for therapeutic change, alone, it is not sufficient.

Visual inspection of the findings suggested that any clinical effectiveness of a value-based approach in isolation was minimal across six participants with mild intellectual disabilities living in community settings, although the limitations of visual inspection and PND analyses should be borne in mind (Danov & Symons, 2008; Parker, Vannest & Davis, 2011). The data (presented in Figures 1 to 4) are, at best, suggestive of a relationship that warrants further scrutiny. However, closer visual inspection of data provided by Wayne and Ryan, indicate some note-worthy findings. For Wayne and Ryan, as self-reported ratings of anxiety and experiential avoidance decreased, self-reported ratings of mood and life satisfaction simultaneously increased. Similarly, there are apparent differences between data provided by male and female participants that warrant further exploration. In contrast to the findings for John, Wayne, Lionel and Ryan, findings for Rose-Anna and Ellie indicated that self-rating scores of anxiety and experiential avoidance remained relatively stable throughout, whilst fluctuation (increases and decreases) in mood and life satisfaction scores for were apparent for Ellie and Rose-Anna respectively. Within ACT, experiential avoidance is considered as the “*primary obstacle preventing individuals from engaging in valued actions*” (Orsillo, Roemer, Lerner & Tull, 2004, p. 76). In Ellie’s case, the findings are congruent with a key element of ACT; the focus on increased willingness and ability to experience aversive feeling

states (such as anxiety) (*'feel the fear'*) whilst developing the capacity to tolerate the states, without letting them influence behavioural choices (*'do it anyway'*; Hayes et al., 2013).

The findings provide a strong retrospective justification for the use of experimental single case designs in the initial stages of a component analysis investigation. The finding that scores for some participants decreased while others increased might well have gone unnoticed in the 'averaging out' process of group statistical analysis. Despite the positive results for some participants, however, it is clear that the adaptation of the values component alone was not sufficient to effect significant therapeutic change more generally.

Component analysis studies provide a methodology whereby relevant variables may be carefully manipulated to evaluate outcomes that would be more difficult to achieve in general outcome research (Levin, Hildebrandt, Lillis & Hayes, 2012) and are particularly rare amongst the field of intellectual disability research. Although adaptation of a single values component did not itself lead to therapeutic change, a number of potentially important discoveries warrant further exploration in the future:

- 1. Participant *understanding* of the concept of values** - can this be enhanced through the use of photography?.
- 2. Self-reported rating of inner world experience** - can people with intellectual disabilities reliably recognise and rate their levels of anxiety, experiential avoidance, mood and life satisfaction via text messages?
- 3. Acceptability of photography** – what was it like for people with intellectual disabilities to talk about photographs of valued aspects of life; did this facilitate an understanding of values in a more literal way?
- 4. Development of a value-based intervention manual** designed specifically for people with intellectual disabilities addressed shortcomings highlighted within

previous review of ACT interventions in the general population (Ost, 2008). As a result of the current research, the *Catching What Matters* intervention manual has been piloted with six participants with intellectual disabilities. The intervention manual may indeed form the basis of further development of future ACT-Intellectual Disability (ACT-ID) concepts.

Ultimately, the current feasibility study provides rich and valuable information to guide future research planning and implementation, potentially representing an early stage preliminary basis of an ACT-ID approach. However, a number of limitations are worthy of note:

1. The findings of *Catching what Matters* are limited due to the relatively small sample size recruited from a small geographical location. Future research may seek to incorporate larger, more diverse samples.
2. Findings were reliant on self-report data, which is subject to potential pressures that may result in inaccurate reporting and may be influenced by social demands imposed by the participant/therapist (e.g. demand characteristics, wider factors within the residential setting). Similarly, while the multiple baseline across participants design does control for external events, it does not account for the non-specific effects of research participation, internal factors or wider systemic factors beyond participant control. Future research may seek to collate simultaneous informant-based ratings alongside participant ratings for comparison purposes directly compare empirical findings with life events.
3. Given the diverse and unique presentations of individuals with intellectual disabilities, the inclusion and exclusion criteria of the current study may render the ecological validity of the current findings questionable/not accurately representative of the population of people with intellectual disabilities more widely.

4. Formal assessment methods were not used for diagnoses within the current study due to the preliminary feasibility nature of the study and its focus on measurement of anxiety, experiential avoidance, mood and life satisfaction as opposed to changes in diagnostic criteria. Collation of formal diagnosis/IQ scores in future research may enable greater comparisons to be made.

Chosen outcome measures (GAS-ID, GDS-LD, GDS-CS, BLESID-SR and BLESID) were specifically designed for use with people with intellectual disabilities and had sound reliability and validity. Reduced anxiety scores, as measured by the GAS-ID in the current study, mirror those found by Pankey and Hayes (2003). Examination of individual improvement using the Reliable Change Index demonstrated reliable change at post-test for John, Wayne, Ellie and Ryan. With the exception of John, all findings were clinically significant indicating that Rose-Anna, Wayne, Lionel, Ellie and Ryan's level of functioning subsequent to *Catching What Matters* was closer to the mean of the 'functional' population (i.e non-depressed sample) than the mean of the 'dysfunctional' sample (i.e. depressed sample). It was unfortunate that it was not possible to calculate Reliable Change Index/Clinically Significant Change for the GAS-ID and GDS-CS due to absence of required psychometric information. This highlights the current status of research/evidence within the intellectual disability field and identifies an area for future research development. Future research investigating values for people with intellectual disabilities may also consider inclusion of ACT specific measures, such as the Acceptance and Action Questionnaire (AAQ; Hayes, Luoma, Bond, Masuda & Lillis, 2006) or Valued Living Questionnaire (VLQ; Wilson & Groom, 2002).

Intentional therapist and researcher blinding to the self-reported rating of dependent variables and session content was ensured in order to minimise potential impact of participant experience of involvement in the research. Self-reported ratings were based on a Likert scale of 1 to 5, accompanied by 'easy-read' thermometers to facilitate rating selection and enhance accessibility for people with intellectual

disabilities. Although seemingly well received, the scale of one to five somewhat limited any potential movement within the scale. Future research may consider inclusion of an alternative rating scale (e.g. a visual analogue scale), ideally co-produced through focus groups comprised of people with intellectual disabilities.

The findings of the current study precede a number of potentially fruitful avenues for future research, both clinically and theoretically. Given the important finding that a value-based intervention may be necessary for therapeutic change, and alone, is not sufficient, future research should seek to determine the precise nature of potential additional factors required to enhance clinical effectiveness through further exploration/modification of ACT components.

Informal qualitative evidence collated anecdotally post-intervention from both participants and therapists during outcome measure completion yielded positive and interesting findings regarding overall experience of involvement with this novel approach. Future research may endeavour to capture such nuances through inclusion of qualitative elements. Furthermore, qualitative information can provide invaluable insight (Hays, Murphy, Langdon, Rose & Reed, 2007), facilitating participant empowerment to share experiences and shape future research endeavours, whilst embracing the spirit of meaningful co-production.

Amidst the current paucity of literature pertaining to ACT for people with intellectual disabilities, the current study represents a valuable, preliminary contribution to the evidence base and an important empirical basis upon which subsequent research ventures may build.

This study has shown that it is possible to isolate a single component of ACT and to adapt it for use with people with intellectual disability. The remaining challenge is to produce similar adaptations for the other components (Acceptance; Cognitive Fusion; Being Present; Self as Context; and Committed Action). The current

study has shown that given sufficient creativity and adaptability, an intervention may be designed that takes into account the “*concrete and linear understanding of thoughts and events*” mentioned by Pankey & Hayes, (2004). Catching What Matters may form the basis of future adaptations.

This study serves to highlight the potential feasibility of a value-based approach for people with intellectual disabilities, augmented through the use of participant-produced photography to enhance conceptual understanding of the values component of ACT. The authors consider this to be a logical, preliminary step towards the initial basis of an ACT- ID evidence base.

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Table 1

Mean and standard deviations of self-reported ratings of target variables every three days during baseline, intervention and follow-up

	Anxiety			Experiential Avoidance			Mood			Life Satisfaction		
	<i>MBaseline</i> (<i>SD</i>)	<i>MInt</i> (<i>SD</i>)	<i>MF/up</i> (<i>SD</i>)	<i>MBaseline</i> (<i>SD</i>)	<i>MInt</i> (<i>SD</i>)	<i>MF/up</i> (<i>SD</i>)	<i>MBaseline</i> (<i>SD</i>)	<i>MInt</i> (<i>SD</i>)	<i>MF/up</i> (<i>SD</i>)	<i>MBaseline</i> (<i>SD</i>)	<i>MInt</i> (<i>SD</i>)	<i>MF/up</i> (<i>SD</i>)
Rose-Anna	3.89 (1.36)	4.05 (1.59)	5.0 (0.00)	3.67 (1.50)	4.14 (1.65)	4.67 (0.52)	1.78 (1.09)	1.67 (1.24)	2.33 (1.21)	1.38 (1.07)	2.33 (2.07)	2.38 (2.13)
John	2.5 (1.26)	2.4 (1.46)	1.6 (0.55)	3.00 (1.03)	2.22 (0.94)	2.00 (0.71)	3.18 (1.38)	3.83 (1.38)	4.60 (0.54)	3.44 (0.81)	4.0 (1.08)	4.20 (0.45)
Wayne	4.0 (1.81)	1.09 (1.06)	1.0 (0.00)	2.87 (2.03)	1.00 (1.0)	1.8 (0.45)	3.06 (2.11)	3.34 (2.24)	5.0 (0.00)	3.06 (2.11)	3.35 (2.25)	5.0 (0.00)
Lionel	1.37 (1.28)	1.38 (1.23)	1.0 (0.00)	1.23 (1.21)	1.06 (0.97)	1.0 (0.00)	3.08 (2.08)	2.58 (2.12)	5.0 (0.00)	3.07 (2.08)	2.59 (2.12)	4.0 (0.00)
Ellie	3.0 (1.41)	3.26 (1.60)	3.8 (0.45)	2.88 (1.55)	3.00 (1.69)	4.0 (0.00)	3.50 (1.51)	4.0 (1.38)	5.0 (0.00)	3.50 (1.51)	4.0 (1.38)	5.0 (0.00)
Ryan	3.17 (1.82)	1.0 (1.0)	1.0 (0.00)	2.94 (1.47)	1.23 (0.88)	1.0 (0.00)	2.89 (1.49)	3.93 (1.83)	5.0 (0.00)	2.89 (1.49)	3.93 (1.83)	5.0 (0.00)

Table 2

Pre and post-intervention outcome measure scores

	John		Rose-Anna		Wayne		Lionel		Ryan		Ellie	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
GAS-ID	32	28	42	32	30	23	22	23	26	17	43	40
GDS-LD	14	12	29	19	21	6	15	15	18	10	24	11
GDS-CS	10	9	12	14	12	10	12	4	11	3	11	5
BLESID ^{SR}	-	4	-	6	-	14	-	2	-	4	-	2
BLESID	-	20	-	13	-	52	-	12	-	6	-	4

Note. Dashes indicate data not collated. GAS-ID = Glasgow Anxiety Scale for people with Intellectual Disabilities; GDS-LD = Glasgow Depression Scale for people with a Learning Disability; GDS-CS = Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability; BLESID^{SR} = Bangor Life Events Schedule for Intellectual Disabilities Self Report Semi-Structured Interview. BLESID = Bangor Life Events Schedule for Intellectual Disabilities

Table 3

Means Standard Deviations and Effect Size for Outcome Measures

Measure	<i>M_{pre}</i> (<i>SD</i>)	<i>M_{post}</i> (<i>SD</i>)
GAS-ID ¹	32.50 (8.48)	27.12 (8.08)
GDS-LD ²	20.17 (5.71)	12.1 (4.45)
GDS-CS ³	11.33 (0.82)	7.50 (4.23)
BLESID ^{SR}	-	5.33 (4.50)
BLESID	-	17.83 (17.67)

Note. Dashes indicate data not collated. *M* = Mean, GAS-ID = Glasgow Anxiety Scale for people with Intellectual Disabilities; GDS-LD = Glasgow Depression Scale for people with a Learning Disability; GDS-CS = Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability; BLESID^{SR} = Bangor Life Events Schedule for Intellectual Disabilities Self Report Semi-Structured Interview. BLESID = Bangor Life Events Schedule for Intellectual Disabilities

Table 4

Individual Improvement, Reliable Change Index and Clinical Significance Scores for the Glasgow Depression Scale for People with a learning disability.

Participant	Pre-Score GDS-LD*	Post-Score GDS-LD*	RCI	Reliable Change? Y/N	Clinically significant? Y/N (<16.32)
Rose-Anna	14	12	1.19	N	Yes
John	29	19	5.95	Y	No
Wayne	21	6	8.93	Y	Yes
Lionel	15	15	0	N	Yes
Ellie	18	10	4.76	Y	Yes
Ryan	24	11	7.74	Y	Yes

Note: * = information from Table 2: GDS-LD = Glasgow Depression Scale for people with a Learning Disability; RCI = Reliable Change Index.

Table 5

Overview of participant session attendance and photographs taken between sessions.

Participant	Sessions attended (%)	Number of new photos taken between sessions						Total No. photos
		Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	
Rose-Anna	100	69	90	0	25	0	47	231
John	100	6	9	5	16	2	4	42
Wayne	100	2	0	2	6	0	0	10
RV	100	19	4	5	0	0	9	37
Ryan	100	5	14	0	4	2	6	31
Ellie	83	14	10	9	-	7	11	51

Note. Dashes indicate non-attendance

Chapter 3 - Contributions to Theory and Clinical Practice

Abstract

The current thesis demonstrated that participant-produced photography was a promising augmentation of therapeutic interventions for people with intellectual disabilities. In what the authors considered to be a logical, preliminary step towards the initial basis of an ACT-Intellectual Disability (ACT-ID) evidence base, an empirical investigation using component-analysis was undertaken. Focusing specifically on the ‘values’ concept of ACT, six community-based participants with mild intellectual disabilities took part. Findings indicated that a value-based intervention alone may be necessary, but was not sufficient for change. This final chapter is dedicated to discussion of implications for future research and theory development arising from the findings of both papers, and the discussion of potential avenues for further adaptation of the ACT model for people with intellectual disabilities. Clinical implications including the use of mobile phones in clinical practice/data collection and value-based approaches for relapse prevention and maintenance of positive well-being are also explored. Process/personal reflections are presented.

Implications for future research and theory development

Findings from the literature review and empirical investigation represent valuable, preliminary contributions to the Acceptance and Commitment Therapy-Intellectual Disability (ACT-ID) evidence base; an important empirical basis upon which subsequent research may build. Considered together, both investigations lend support to the use of novel approaches (e.g. participant-produced photography and text-message data collection) to facilitate understanding of potentially abstract theoretical concepts, such as ‘values’. As such, a number of implications for future research and theory development warrant further exploration.

Component Analyses

Component analysis studies are rare in the literature pertaining to therapeutic interventions. This is unfortunate due to the potential value of identifying/isolating mechanisms of change. For example, in their examination of the active elements of cognitive behaviour therapy (CBT), Jacobson et al. (1996) found that the model’s cognitive components did not add to treatment effectiveness and was equal in efficacy to behavioural activation. This search for the active component of an intervention led to important, and counter-intuitive findings that would not have been possible without the use of component analysis methodology.

Drawing on challenges identified amongst the literature regarding facilitation of full engagement with aspects of the ACT model, both for people with intellectual disabilities (e.g. Brown & Hooper, 2009) and those without (e.g. Wilson & Murrell, 2004), the current empirical investigation isolated a single component of the ACT model (values). Participant-produced photography enabled

augmentation of an abstract concept, demonstrating a key component of ACT may be meaningfully accessed by people with intellectual disabilities.

As a model, ACT can be defined in terms of six psychological processes that revolve around a single core concept (Hayes, Pistroello & Levin, 2012, p. 981). Further component analyses of individual elements represent a logical direction for future research.

Component Analyses of ACT in the general population

Component analyses ('dismantling studies;' Gaudiano, 2011, p. 59) attempt to 'unpack' the efficacy of a multi-component treatment by experimentally isolating and systemically testing the effects of its components separately (Kazdin, 1998). Component studies of ACT have demonstrated consistently positive outcomes within the general population (e.g. Levitt, Brown, Orsillo and Barlow, 2004; Masuda et al., 2009). A meta-analysis of laboratory-based ACT component studies found that effect sizes for conditions including experiential methods (e.g. metaphors and exercises) ($g = .48$, 95% CI = .34, .61, $z = 6.81$, $n = 31$) were significantly larger than conditions using rationale alone ($g = -.15$, 95% CI = -.46, .17, $z = -.92$, $n = 5$). This suggests that elements of the ACT model have a greater impact on psychological outcomes when they include interactive elements such as the use of metaphors and experiential exercises, compared to verbal explanations/rationale-alone (Levin, Hildebrandt, Lillis & Hayes, 2012). A component analysis of ACT examining the 'self-as-context' element is currently underway (Stockton, 2014) in the general adult population, the findings of which may lend support to future ACT-ID research endeavours.

Component analyses of ACT for people with Intellectual Disabilities

There is an important ethical balance between the delivery of effective evidence-based approaches versus absence of delivery due to lack of evidence - as opposed to evidence of ineffectiveness (Osugo & Cooper, 2016). The current thesis has demonstrated a way in a language-laden approach may be tailored to for people with intellectual disabilities. A future research implication is therefore, the need for enhanced accessibility of the remaining components of the ACT model. Such endeavours would rely on clinician creativity, underpinned by existing evidence across a wide range of specialisms to develop/augment therapeutic approaches for people with intellectual disabilities.

A number of potential adaptations of therapeutic approaches for people with intellectual disabilities have been outlined in recent literature (e.g. mindfulness and acceptance based approaches, Gore & Hastings, 2016; psychodynamic therapy, Beail, 2016; CBT, Jahoda, 2016; cognitive analytic therapy, Beard, Greenhill & Lloyd, 2016; dialectical behaviour therapy, Lippold, 2016; solution-focused brief therapy, Lloyd, MacDonald & Wilson, 2016). Future ACT-ID research endeavours may draw on the suggested adaptation, some of which are outlined below:

Visual methods

- Incorporation of visual aids e.g. the ‘*Blob People*’ (Wilson, 2004), flip-charts, thought/speech bubbles to represent possible interpretations of events/noticing thoughts (Wilner, 2009; Whitehouse, Tudway, Look & Kroese, 2006); objects to make abstract concepts concrete e.g. a ‘glitter ball’ for use when discussing feelings (Miodrag, Lense & Dykens, 2012).

- Painting/modelling with clay (Beard, Greenhill & Lloyd, 2016), cutting out pictures from magazines/participant-produced photographs, making a collage to represent aspects of the ACT psychological flexibility model.
- A ‘session-tracker’ e.g. a pie chart divided into total number of planned sessions, shaded by client at the end of each session to represent completion.

Practical exercises

- Action-orientated approaches e.g. art/drama/music therapies (requiring minimal reliance on cognitive or verbal abilities).
- Role plays to explore emotions and outcomes (Wilner, 2009; Whitehouse, Tudway, Look & Kroese, 2006).
- ‘Self-modelling’ – client develops and views a film/DVD of themselves engaged in desired behaviours/valued activities (Murphy & Davis, 2005).
- Practical mindfulness exercises to enhance literacy of concepts e.g. mindful walking (Peterson, 2015); blowing bubbles (Robertson, 2011); Soles of the Feet (SoF) meditation (Singh et al., 2011).

Improving accessibility/overcoming barriers

- Simplifying/re-wording complex language (Lippold, 2016).
- Audio/DVD (or mobile phone) recordings as an alternative to literacy based therapeutic activities e.g. home-tasks, personal diary records and facilitation of between session-generalisation (King, 2000; Jahoda, 2016).

Based on some of the, recommended adaptations of therapeutic interventions for people with intellectual disabilities, future ACT-ID research endeavours

may further adapt the ACT package, drawing on a potential example of how this may look, outlined in Figure 1.

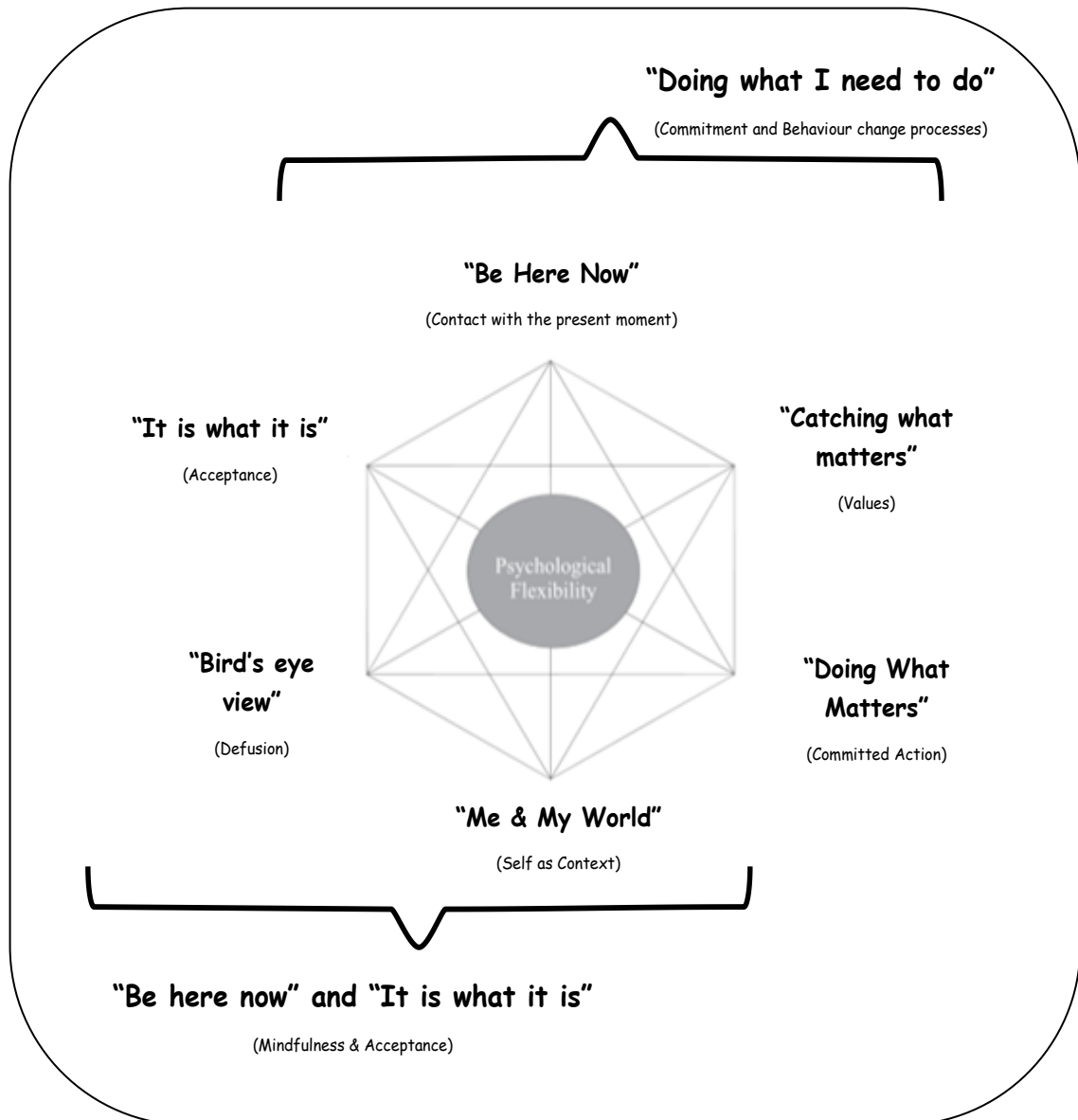


Figure 1. Prospective ACT-ID Model of Behaviour Change (adapted from Hayes, Pistorello & Levin, 2012, p. 981).

Factors for consideration in future ACT-ID research endeavours:

Awareness of therapeutic pace. Previous research has highlighted the need to incorporate additional session time into programmes to allow time for idea processing and practical application of concepts through experiential exercises (e.g. Brown & Hooper, 2009; Pankey & Hayes, 2008). The duration of the current empirical investigation was extended due to stipulations made by the Research Ethics Committee regarding the perceived burden of daily responses to text messages. This rendered the intervention longer than initially anticipated. Future research may seek to initially evaluate the feasibility daily text messages and subsequently develop research that obtains more frequent self-reported ratings of outcome variables, for a shorter duration of time. For example, one participant suggested a four session, fortnightly intervention in the future to allow time to practice taking photos of valued aspects of life to talk about in-session.

Supporter involvement: Client engagement and understanding may be facilitated through involvement of supporters, not only in-session, but to encourage practice of concepts learned in-session outside of sessions (Gore & Hastings, 2016). This may also support participants to develop their own understanding and personal practice of principles covered e.g. identification and increased focus on valued aspects of life which have been indicated as useful (Noone & Hastings, 2009; Bethay, Wilson, Schnetzer, Nassar & Bordieri, 2013). The manualised intervention approach alongside the current thesis lends itself well to inclusion of supporters, with the potential for development of handouts/home-tasks for reference between sessions.

Future research may also consider:

- Further exploration of photography and data collection via text messages as a research method.
- Development of an ACT-ID outcome measure, to facilitate comparison across the findings of future research endeavours. This may incorporate adaptations of existing measures such as the Questionnaire (AAQ; Hayes, Luoma, Bond, Masuda & Lillis, 2006) or Valued Living Questionnaire (VLQ; Wilson & Groom, 2002) or evaluate the development of a specific ACT-ID measure, ideally generated through the use of focus groups/embracing the spirit of co-production from the outset.

Ultimately, further component analyses of the remaining ACT components would represent a logical avenue for future research. Multiple baseline methodologies have been recommended for such endeavours (Longmore & Worrell, 2007). This is highlighted within the empirical findings of the outcome measures in the current investigation; apparent ‘significant’ findings may be less clinically important when compared to individual data. Accessibility enhancement should be the focus of future research with people with intellectual disabilities (i.e. making abstract concepts concrete). Some potential examples are outlined in Table 1 (see also Pankey & Hayes, 2008).

Table 1.

Potential adaptations of ACT components for further research

ACT Concept	ACT-ID Adaptation of Concept	Potential Exercises
Acceptance	“It is what it is”	Experiential mindfulness activities e.g. Walking mindfulness (Peterson, 2015), Soles of the Feet Meditation (Singh et al., 2011) e.g. balancing eggs. Music therapy (conflicting sounds, e.g. musical instruments/ radio/voice/mobile phone tracks & attempts to concentrate on task in hand).
Contact with the present moment	“Be here now”	e.g. adaptation of ‘Leaves on a stream’ exercise. Collaborate with client to develop a derivative (e.g. balloons with post-it notes – to be popped or let go). Client to write/draw/say thoughts to the object as they notice them in their mind. Watch the object & thought float away).
Committed Action	“Doing what matters”	Facilitate recall/overcome barriers to engagement through facilitation or supporter (family/paid staff involvement) and co-production of creative reminders about actions e.g. alarms set on mobile phone, posters/creative notes placed in convenient locations. Provision of a ‘role’ for undertaking actions, e.g.

		photography – a ‘mission to take photographs when engaged in valued aspects of life’ (closely linked to ‘catching what matters.’)
Self as Context	“Me and my world”	Use of ‘self-modelling’ (Murphy & Davis, 2005) – participant may create a film (e.g. using a mobile phone) of themselves engaged in valued activity. Watch the clip back (with therapist/staff/independently) and notice self in the surroundings – as an aspect of a wider context. Virtual reality equipment (e.g. research using multiple baseline-design)
Defusion	“Bird’s eye view”	Activities that foster awareness of thoughts. E.g. Photography. Clients may capture images of aspects of life (e.g. self) and practice defusion. E.g. “that’s a chair; that’s a photograph of a chair/ that’s a person who is.../that’s a picture of a person who is...” encouraging mindful noticing of wider aspects of the image/inclusion of thought bubbles which can be amended e.g. on a computer package/in-session with participant.

Implications for Clinical Practice

Perhaps the most significant clinical implication to emerge from the current empirical investigation was the finding that a component of an abstract, language-laden therapeutic approach (ACT) was amenable to augmentation (through participant produced photography) in a way that facilitated meaningful access for people with intellectual disabilities. This thesis highlights that people with intellectual disabilities were able to engage with and understand the concept of values. This finding is not restricted to ACT and may be an important consideration for adaptation of other therapeutic approaches for people with intellectual disabilities such as Dialectical Behaviour Therapy (DBT; Linehan, 1993), Cognitive Analytic Therapy (CAT, Ryle, 1990) and Compassion-focused Therapy (Gilbert, 2009).

Considered broadly, ACT has shown promise across a number of settings, including education (Schonfeld, 1990); parenting skills interventions (Blackledge & Hayes, 2006), occupational settings (Bond & Bunce, 2003; Donaldson & Bond, 2004) and in medical care (Lundgren, Dahl, Melin & Kees, 2006), where improvements in factors including medication compliance, work performance and reduced stress/burnout levels in teachers have been demonstrated following engagement with ACT interventions. Therefore, the clinical implications of the current thesis may ultimately be considered across a wide range of clinical settings.

Values system: a stable base in an unpredictable world

People with intellectual disabilities are more likely to be exposed to traumatic life events than the general population (Hatton & Emerson, 2004) given

the unique circumstances of their lives (Levitas & Gilson, 2001). Subsequently, recognition of a consistent set of ‘protective factors’ (often drawn on within clinical formulation) may be difficult. Protective factors frequently draw on elements of life which lie outside of client control (e.g. engaging in activities, spending time with particular people). As such, protective factors may be transient and sometimes, simply absent (e.g. loss, financial resources, political climate). ACT encourages individuals to “*make room for life’s difficulties*” (Hayes, Strosahl, & Wilson, 1999, p. 81) and move in the direction of their chosen values, even in the face of difficulty (Biglan, Hayes & Pistorello, 2008). ACT emphasises individual ability to control some things, and not others; clients are encouraged to exercise control in areas of life where control *is* effective (Hayes, 1994). Essentially, the ability to articulate a readily available and easily accessible values system, during times of adversity, represents a key clinical implication arising from the current thesis, a concept captured by a research participant: “*when I worry, I just think, there’s no need to worry, just look at the pictures and think I’ve got lots of things to value.*”

Values: implications for relapse prevention

The capacity to recognise, articulate and draw on a personal value system which may be readily accessed during times of difficulty holds promise for use with a variety of individuals across a wide range of settings. *Catching What Matters* helped participants to hone their ability to foster awareness of their own values system. Participant produced photography facilitated frequent rehearsal of this. ACT may be particularly valuable in preventing the onset/relapse of mental health issues across mental health settings. Bach and Hayes (2002) found that four

sessions of an individual acceptance intervention reduced rates of hospitalisation over a 4-month period by 50% amongst a group of inpatients experiencing the positive symptoms of psychosis. Participants within the ACT condition were considerably more likely to report symptoms than Treatment as Usual participants. Such research highlights the potential clinical implications of the current empirical investigation, not only for people with intellectual disabilities, but as a wider approach.

Values: Implications for Maintenance of Well-being

Some research indicates that value-based approaches may facilitate maintenance of positive well-being; Kasser and Ryan (1996) found that placing strong importance on intrinsic aspirations (values) was positively associated with well-being indicators such as self-esteem and the inverse of depression and anxiety. These findings were replicated across cultural contexts (Ryan et al., 1999) and extend beyond the concept of 'well-being.' Sheldon and Kasser (1998) suggested that well-being was enhanced by attainment of intrinsic goals (values) compared to attainment of extrinsic goals. Together, the results suggested that individuals who pursue extrinsic goals that do not fulfil basic psychological needs may experience less than optimal well-being (Ryan & Deci, 2000). This further highlights important implications of the current research for clinical practice.

Use of mobile phones

Catching What Matters has shown that the use of simple mobile phones and automated text message technology was feasible for use with six community-based participants with intellectual disabilities. This is a viable clinical implication and raises the possibility of incorporation of mobile phones across

community intellectual disability/mental health teams more widely. The mobile phones provided to participants were inexpensive (£10.00) and had a number of features, including a camera. Although there appears to be a paucity of research pertaining specifically to the use of mobile phones for people with intellectual disabilities, general population findings have shown that text messages are a promising tool for gathering data for research and clinical purposes. The method is cheap and simple, allowing rapid communication with people involving minimal disturbance (Whitford et al., 2012). Text messages have also been used for delivering behaviour change interventions (Cole-Lewis & Kershaw, 2010), scheduled appointment reminders (Downer, Meara & Da Costa, 2005; Bobrow et al., 2014) and support with disease control.

Although promising, potential limitations should be borne in mind when considering implementation of text message methodologies in research/clinical practice (Patanik, Brunskill & Thies, 2008). These include reliance on basic literacy skills and dexterity. These may be overcome through involvement of supporters to support text message reading/replying; specialist, adapted mobile phones may be considered, although the cost implications of this should be borne in mind.

Evidence of positive engagement with the text message/mobile phone approach was apparent through qualitative feedback from a number of participants who commented that the mere act of reviewing/'checking-in' with how they were feeling encouraged a shift in behaviour, e.g. if a mood score was low, they would direct themselves to a pleasurable activity in order to address this. Development of a sense of achievement through mastering the mobile phone system was also

apparent: *“I’m good at this...I felt cheerful doing it because I’ve started something and stuck with and persevered with it.”*

Reflective Commentary

“Rollercoaster,” “spinning plates,” “expect the unexpected,” and *“determination in the face of adversity”* are all phrases that spring to mind as I reflect on this research journey. Nobody ever said this would be ‘easy; and at the same time, I had not quite anticipated the trajectory of the road that lay ahead. We have quite literally explored new research territory, the “novelty” of which became apparent at an early stage.

The Research Process

Research Ethics Committee (REC). Having meticulously prepared the research proposal, I attended the REC (accompanied by a very supportive supervisor). Arriving to a ‘sea of (20+) faces’ who had scrutinised our research proposal with a fine tooth comb, it became apparent that this would not be as straight forward as I had hoped. Largely based on our proposed use of novel methodologies, the REC suggested that we made a number of amendments; *“this was not in the research plan.”* I began to doubt my *ability* to do this: *“I should have done something simple; I should have done something that’s been done before.”* Reflective supervision has since led me to wonder whether the most difficult aspect of this unanticipated twist was not the sense of ‘*rejection/not being good enough,*’ yet underpinned by my tendency to self-impose demands; this ‘*set-back*’ had ‘*scuppered my [self-imposed] plans.*’ I had no other option but to tolerate this uncertainty, a skill which became invaluable for the remainder of the research journey.

A (small) contribution to the intellectual disabilities evidence base. This thesis has been driven by my passion to strive to empower people with intellectual disabilities and to encourage equitable access to therapeutic approaches through creativity. Whilst working alongside people with intellectual disabilities in a variety of roles prior to DClinPsy training, the conclusion “*evidence for people with intellectual disabilities is sparse/absent*” became all too familiar. Despite unanticipated ‘*set-backs,*’ and fleeting doubts in *my own* mind, *not once* did I doubt the premise of the research. I wanted to do something to further develop the sparse intellectual disabilities evidence base. Conversely, the set-backs enhanced my determination, particularly in relation to clarification of methodological concepts to the REC. I was later grateful to the panel for the stipulations, which ultimately led to the development of a far more robust research methodology, which facilitated management of queries as they arose during the research process.

Personal Reflections

Clinician/Research Dialectic. As a naturally caring and inquisitive person, I was acutely aware at times of the need to effectively manage the boundary between ‘researcher’ and ‘clinician.’ Reflective supervision supported my management of this; a number of points were apparent:

- i) **Duration.** Research participation was lengthy in some cases (approximately six months). This is a considerable portion of a participant’s life. I believe that my clinical skills as a member of a multi-disciplinary team helped to facilitate continued engagement with both participants and supporters (family carers/paid staff) which was essential

in terms of continued engagement with the research and text message process.

- ii) **Endings.** It was important to be clear about endings from the start, clarity around which was hindered by the nature of the multiple baseline design and the need to await baseline stability. This rendered an absolute time scale difficult to determine. It was particularly positive during follow-up data collation to hear that both participants and staff teams were keen to find out the outcome of the research, interested in progress and the contribution of the research to the evidence base.

Conclusion

Completion of *Catching What Matters* has facilitated dissipation of a comment made by a facilitator of the first research session in 1st year of DCLinPsy training (“*there is no need to look so worried*”). Unanticipated ‘ethical obstacles,’ participant recruitment difficulties, text message data collection and exploring new research territory has inadvertently honed a number of useful skills (both personally and professionally): to: i) *effectively tolerate uncertainty* ii) *have faith in my own ability, strength in my own belief* and iii) “*feel the fear and do it anyway.*” Participant enthusiasm and incessant installation of self-belief from research supervisors, enables me to reflect on the process with a sense of pride. Attachment to the methodology and enthusiasm to/encourage others to further develop the ACT-ID evidence base has flourished throughout this thesis journey.

Summary

Interventions that support people to accept difficult thoughts and feelings and focusing on effective action hold promise for future research endeavours. Development of an empirical evidence base is not only critical to the establishment of new services or interventions, but also necessary to support the value of existing services (Oliver et al., 2002). Efforts should be made by professionals, researchers and user and carer groups to support such research endeavours (Bhaumik, Gangadharan, Hiremath & Russell, 2011). Further research examining individual components represents a logical way forward in terms of development of an ACT-ID evidence base; single component analyses of isolated aspects of ACT are required in order to work towards identification of mechanisms of change. Overall, this thesis serves to highlight the potential feasibility of a value-based approach for people with intellectual disabilities, augmented through the use of participant-produced photography to enhance conceptual understanding of the values component of ACT. The authors consider this to be a logical, preliminary step towards the initial basis of an ACT- ID evidence base.

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Chapter 4 – Appendices

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Appendix A – Bangor University, School of Psychology Ethics Committee Application,
Approval & Bangor University Indemnity Insurance Certificate

Application for Ethical Approval

Project Title: Life through a lens: Auto-photography and anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

Principal investigator: Boulton, Natalie

Other researchers: Williams,Jonathan, Jones,Robert

Pre-screen Questions

Type of Project

D.Clin.Psy

Further details: The current research will be undertaken as part of the North Wales Clinical Psychology Programme (DClinPsy).

What is the broad area of research Clinical/Health

Funding body

Internally Funded

Further details: The project will be funded by the North Wales Clinical Psychology Programme as part of the D.Clin.Psy.

Type of application (check all that apply)

A new application that does not require sponsorship or scrutiny from an outside body?

Proposed methodology (check all that apply)

Other type of research, please specify

Further details: Participants will be required to respond to a series of four questions via text message daily. The questions will require the participant to rate self-reported levels of mood, anxiety, experiential avoidance and life satisfaction on a scale of 1-5. The responses will be collated by the researcher and single case experimental design methodology will be utilised.

Do you plan to include any of the following groups in your study?

Participants who are adults who may not be able to consent for themselves through physical or mental incapacity

Further details: All participants will be recruited from the BCUHB Adult Learning Disability service. Capacity to consent will be ascertained through functional assessment of capacity (Further details available in attached document).

If your research requires any of the following facilities MRI, TMS/ tCS, Neurology Panel, has the protocol been reviewed by the appropriate expert/safety panel?

Not applicable (the research does not require special safety panel approval)

Connection to Psychology, (i.e. why Psychology should sponsor the question)

Investigator is a staff member in Psychology (including the North Wales Clinical Psychology Programme)

Further details: Investigator is currently in the second year of the North Wales Clinical Psychology Programme.

Does the research involve NHS patients? (NB: If you are conducting research that requires NHS ethics approval make sure to consult the Psychology Guidelines as you may not need to complete all sections of the Psychology online application) Yes, NHS IRAS application attached.

Has this proposal been reviewed by another Bangor University Ethics committee? No

NHS checklist. Does your study involve any of the following?

Involve research participants identified from or because of their past or present use of NHS services. Including participants recruited through these services as healthy controls?. Use of NHS Staff or resources e.g. recruitment through the NHS, access to Medical records, use of premises etc.

Further details: Use of NHS Staff: Experienced health professionals working within the BCUHB Community Adult Learning Disability team will meet with participants to discuss the content of the photographs they have taken of valued aspects of their life. This will be incorporated as part of routine clinical practice under the job specification of 'research.'

Part 1: Ethical Considerations

Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?

Yes

Further details: All participants will receive a participant information sheet, which they may read either alone or may be supported to do so. This will include a thorough outline of what they should expect if they provided consent to participate in the research.

Will you tell participants that their participation is voluntary?

Yes

Further details: Both the participant information sheet and the consent form will re-iterate to participants that their participation is voluntary and that they may change their mind/withdraw consent at any stage during the process.

Will you obtain written consent for participation?

Yes

Further details: Written consent will be obtained and recorded on the consent form (Included as an attachment to this document).

If the research is observational, will you ask participants for their consent to being observed? N/A

Will you tell participants that they may withdraw from the research at any time and for any reason? Yes

With questionnaires, will you give participants the option of omitting questions they do not want to answer?

Yes

Further details: If a participant does not wish to reply to any of the four daily text messages at any one time, this will be acceptable and will not automatically necessitate that the remainder of their results will be excluded from the main findings.

Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?

Yes

Further details: It will be made clear within the participant information sheet and consent form that all data will be treated with full confidentiality and if published, anonymity will be maintained.

Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?

Yes

Further details: All participants will receive an easy read summary of the research findings and implications.

Will your project involve deliberately misleading participants in any way?

No

Further details: Participants will be aware of the research outline from the outset. Participants will not be deliberately misled in any way.

Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If *Yes* , give details and state what you will tell them to do should they experience any problems (e.g., who they can contact for help)

Yes

Further details: A potential risk may lie in that the possibility that by asking participants to consider their levels of mood, anxiety, experiential avoidance and life satisfaction, it may exacerbate negative emotions that they are already experiencing. Participants will be advised, that should they experience any low mood or psychological distress, seek help from their usual support network and to visit the GP or A E if necessary.

Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?
No

Does your project involve work with animals? If *Yes* please complete Part 2: B
No

Does your project involve payment to participants that differs from the normal rates? Is there significant concern that the level of payment you offer for this study will unduly influence participants to agree to procedures they may otherwise find unacceptable? If *Yes* please complete Part 2: B and explain in point 5 of the full protocol
No

If your study involves children under 18 years of age have you made adequate provision for child protection issues in your protocol?
No

If your study involves people with learning difficulties have you made adequate provision to manage distress? Yes

If your study involves participants covered by the Mental Capacity Act (i.e. adults over 16 years of age who lack the mental capacity to make specific decisions for themselves) do you have appropriate consent procedures in place? NB Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance N/A

If your study involves patients have you made adequate provision to manage distress? Yes

Does your study involve people in custody? No

If your study involves participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel then has the protocol been reviewed by the appropriate expert/safety panel? N/A

If your study includes physically vulnerable adults have you ensured that there will be a person trained in CPR and seizure management at hand at all times during testing? N/A

Is there significant potential risk to investigator(s) of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research)?

No

Is there significant potential risk to the institution in any way? (e.g., controversiality or potential for misuse of research findings.)

No

Part 3: Risk Assessment

Is there significant potential risk to participants of adverse effects?

No

Is there significant potential risk to participants of distress?

No

Is there significant potential risk to participants for persisting or subsequent illness or injury that might require medical or psychological treatment?

No

Is there significant potential risk to investigator(s) of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research)? No

Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)

No

Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends? No

Does the experimental procedure involve touching participants? No

Does the research involve disabled participants or children visiting the School?

No

Declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Policy, and that this research will comply with them. Yes

Declaration of risk assessment The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research. Yes

Declaration of conflict of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research. Yes

Part 2: A

The potential value of addressing this issue

Hypotheses

Participants recruitment. Please attach consent and debrief forms with supporting documents

Research methodology

Estimated start date and duration of the study.

For studies recruiting via SONA or advertising for participants in any way please provide a summary of how participants will be informed about the study in the advertisement. N.B. This should be a brief factual description of the study and what participants will be required to do.

Part 2: B

Brief background to the study

The hypotheses

Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Research design

Procedures employed

Measures employed

Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)

Venue for investigation

Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).

Data analysis

Potential offence/distress to participants

Procedures to ensure confidentiality and data protection

*How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)

Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.

Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)

Payment to: participants, investigators, departments/institutions

Equipment required and its availability

If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.

Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

Amendment form

Participants' ability to give informed, voluntary consent

Yes

Participants' ability to voluntarily withdraw from the research Yes

In questionnaire-based studies, participants' option to omit questions Yes

Maintenance of confidentiality of participant data

Yes

The ability to give a full participant debriefing

Yes

Risks to participants, investigators, or the institution Yes

Do you intend to use additional questionnaires, please attach copies with supporting documents. Yes

Does the nature of your request entails changes to consent/debriefing information, please attach the amended documents with supporting documents.

Yes

Amendment declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Handbook, and that this research will comply with them. Yes

Declaration of risk assessment: The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research. Yes

Declaration of conflicts of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research. Yes

Declaration of data ownership and IPR (for students): I understand that any data produced through this project are owned by the University and must be made available to my supervisor on request or at the end of the project. I confirm that I am aware of the University's Intellectual Property Policy and that this research will comply with it. Yes

Part 4: Research Insurance

Is the research to be conducted in the UK? Yes

Research that is based solely upon certain typical methods or paradigms is less problematic from an insurance and risk perspective. Is your research based solely upon one or more of these methodologies? Standard behavioural methods such as questionnaires or interviews, computer-based reaction time measures, standardised tests, eye-tracking, picture-pointing, etc; Measurements of physiological processes such as EEG, MEG, MRI, EMG, heart-rate, GSR (not TMS or tCS as they involve more than simple 'measurement'); Collections of body secretions by non-invasive methods, venepuncture (taking of a blood sample), or asking participants to consume foods and/or nutrients (not including the use of drugs or other food supplements or caffeine).

Yes

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689



TO WHOM IT MAY CONCERN

1 August 2014

Dear Sir/Madam

**BANGOR UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:-

1. EMPLOYERS' LIABILITY

Certificate No.	Y016458QBE0114A/026
Period of Cover	1 August 2014 to 31 July 2015
Limit of Indemnity	£25,000,000 any one event unlimited in the aggregate.
Includes	Indemnity to Principals
Cover provided by	QBE Insurance (Europe) Limited and Excess Insurers.

2. PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.	UM026/95
Period of Cover	1 August 2014 to 31 July 2015
Includes	Indemnity to Principals
Limit Of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Susan Wilkinson'.

Susan Wilkinson
For U.M. Association Limited



U.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW
Registered in England and Wales No. 2731799

Appendix A. Bangor School of Psychology email confirmation of ethical approval

From: e.mcquarrie@bangor.ac.uk <e.mcquarrie@bangor.ac.uk>
Sent: 13 July 2015 08:49
To: Natalie Elizabeth Boulton
Subject: Ethical approval granted for 2015-14207-A13330 Amendment to to Life through a lens: Auto-photography and anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

Dear Natalie,

2015-14207-A13330 Amendment to to Life through a lens: Auto-photography and anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

Your research proposal number 2015-14207-A13330 has been reviewed by the Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix B – Integrated Research Application System (IRAS) Form

Research Ethics Committee (REC) Opinion Letter (unfavourable)

Summary of how issues raised by the REC were addressed

REC Opinion Letter (Conditional approval - subject to amendments)

Response to request for further information

REC Favourable Opinion Letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.

Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Ysbyty Gwynedd Hospital Clinical Academic Office

Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877

Email: Rossela.Roberts@wales.nhs.uk

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Miss Natalie Boulton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
43 College
Road, Bangor,
Gwynedd
LL57 2DG

psp2cd@bangor.ac.uk

20 February 2015

Dear Miss Boulton,

Study title: Life through a lens: Auto-photography and anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

REC reference: 15/WA/0038

IRAS project ID: 167267

The Research Ethics Committee reviewed the above application at the meeting held on 19 February 2015. The Committee wishes to thank you and Dr Williams for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Dr Rossela Roberts, rossela.roberts@wales.nhs.uk

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

Ethical opinion

The members of the Committee present decided to issue an unfavourable opinion for the following reasons:

1. The research protocol should include a detailed explanation of the methodology employed as well as a justification of the analysis plan. The Committee suggested that the applicants consider presenting the protocol as a pilot study as the outcome measures identified will not adequately answer the research question. A feasibility/pilot study will establish how feasible it is to apply the technique in this group of participants.
2. The burden imposed on participants is disproportionate in relation to the direct benefit participants will derive from taking part in the study. The frequency of the text messages to be answered by participants will need to be reconsidered and reduced.
3. The Committee noted that the conduct of the research as proposed would raise severe data protection and confidentiality issues; if participants use their own mobile phone and camera, the privacy policy of the web based platform (Firetext service) and the in-phone applications providers' needs to be considered.

The Committee suggested that confidentiality issues can be addressed by replacing the use of personal mobile phone; participants should be provided with an inexpensive mobile phone with incorporated camera, registered to the research team not to the individual participant - which would preserve their anonymity and confidentiality.

4. The Information Sheet does not adequately ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate. The Participant Information Sheet should list clearly all study procedures (including the psychometric tests), it should explain how quotations will be used, and ensure that if participants are distressed they are referred to relevant services/healthcare professional not the Emergency Department. If participants are directed to contact their GP, a GP letter should be issued to outline the study and inform that the patient has consented to take part.
5. The summary of the study as it appears in section A6-1 of the REC application form was not deemed to be an accurate description of the study and not suitable for publication on the NRES website; the summary of the study would need to be re-written to adequately describe in lay terms the aim of the project and the methodology.

I regret to inform you therefore that the application is not approved.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Dr Rossela Roberts at the address in the letterhead.

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application.

We strongly recommend that you submit the new application to this REC. In order to arrange for the new application to be reviewed by this REC, please contact Dr Rossela Roberts when you have prepared the new application in order to book a slot at the meeting. If you prefer, you may submit the application to a different REC by contacting the Central Booking Service. Please note, you must be able to submit the application on the same day as making the booking.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Catherine Blewett
HRA Improvement & Liaison Manager
National Research Ethics Service

Email: catherineblewett@nhs.net

Summary of discussion at the meeting

The Chairman welcomed you and Dr Williams and introduced the Committee members.

The following issues were discussed:

Social or scientific value; scientific design and conduct of the study

The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol and concluded that the

research question was highly appropriate but the research design and the proposed analysis are inadequate to answer the research question.

The research protocol is not clear on how the primary outcome measure will be assessed and the procedures have not been adequately described (what will happen, in what order) You clarified that 6 participants will be recruited and divided into 2 groups of 3 participants each. In accordance to the methodological rigours of the multiple baseline single case experimental design, each participant will be assessed for the scores on 4 dimensions which are plotted on a graph and analysed. Participants will not run concurrently to control for baseline stability.

The Committee requested that the protocol includes a detailed explanation of the methodology employed as well as a justification of the analysis plan. The Committee felt that a statistical analysis of the data points on the plot should be possible and requested a clarification of how various inter-participant confounding factors will be accounted for in the absence of sub-group analyses (e.g. first language English, first language Welsh, male/female, age, etc)

You clarified that no comparison will be made between participants, the aim of the single case design is to track individual progress.

The Committee requested that the applicants consider presenting the protocol as a pilot study as the outcome measures identified will not adequately answer the research question. A feasibility/pilot study will establish how feasible it is to apply the technique in this group of participants.

Favourable risk benefit ratio; anticipated benefit/risks for research participants

The Committee discussed the anticipated benefits and potential risks to participants and was satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants.

The Committee queried whether the burden imposed by the study is not disproportionate in relation to the direct benefit for the participant; text messages to be answered 4 times day for 11 weeks were considered excessive.

You clarified that the duration of 11 weeks is an absolute maximum; the length of the intervention is in fact 6 weeks

The Committee requested that disproportionate burden is addressed by reducing the frequency of the text messages.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality

The Committee discussed the arrangements made to protect privacy through confidentiality as well as the information governance aspects of the study, where and for how long will data be stored, and clarified who will have access to the data.

The Committee noted that the conduct of the research as proposed would raise severe data protection and confidentiality issues, if participants use their own mobile phone and camera. You confirmed that the study team intend to use Firetext, a web-based SMS marketing platform to send the texts to participants, and receive participants' replies.

The Committee requested a clarification in relation to the privacy policy of the web based platform (Firetext service), and queried whether the research team has received reassurances in relation to the confidentiality ensured by the service.

Similarly, if participants will use their own mobile phone to take photographs, several apps have access to the pictures folder and they can be uploaded to other applications (such as Facebook and Instagram, etc) – and therefore the confidentiality policy of each of the providers needs to be considered.

The Committee suggested that all confidentiality issues can be address by replacing the use of personal mobile phone; participants should be provided with an inexpensive mobile phone with incorporated camera, registered to the research team not to the individual participant - which would preserve their anonymity and confidentiality.

Informed Consent process and the adequacy and completeness of participant information

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. There is no inducement or coercion, but the information is not very clear as to what the participant consents to. The Committee requested that amendments should be made to ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate. The information sheet should be written consistently in the first person or third person and it should list clearly all study procedures (including the psychometric tests), should explain how quotations will be used, and ensure that if participants are distressed they are referred to relevant services/healthcare professional not the Emergency Department. If participants are directed to contact their GP, a GP letter should be issued to outline the study and inform that the patient has consented to take part.

Suitability of the study summary

The summary of the study as it appears in section A6-1 of the REC application form was not deemed to be an accurate description of the study and not suitable for publication on the NRES website,; the summary of the study would need to be re-written to adequately describe in lay terms the aim of the project and the methodology

The Chairman thanked you and Dr Williams for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

The Chairman confirmed that the Committee will deliberate and will be in touch shortly.

The applicants left the room.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Based on the information provided, the Committee was satisfied with the following aspects of the research:

- Recruitment arrangements and access to health information, and fair participant selection
- Informed consent process and the adequacy and completeness of participant information
- Suitability of the applicant and supporting staff
- Independent review
- Suitability of supporting information
- Other general issues

The Committee identified issues with the following aspects of the research:

- Social or scientific value; scientific design and conduct of the study
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity • Suitability of the summary of the research

Documents reviewed

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC Application Form [REC_Form_22012015]	-	22 January 2015
Research protocol or project proposal [Research Protocol]	1	20 January 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Visual representation of proposed methodology]	1	20 January 2015
Letters of invitation to participant [Opt-in form for potential participants]	1	20 January 2015
Participant information sheet (PIS) [Participant Information Sheet]	1	20 January 2015
Participant consent form [Participant Consent Form]	1	20 January 2015
GP/consultant information sheets or letters [Clinician information sheet]	1	20 January 2015
Other [Example SMS Text Messages]	1	20 January 2015
Other [Guidelines for the functional assessment of capacity]	1	20 January 2015
Referee's report or other scientific critique report [School of Psychology Research Ethics and Governance Committee Review - 14207]		05 January 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance Certificate Bangor University]	v.1	01 August 2014
Summary CV for Chief Investigator / Student [Miss Natalie Boulton]	-	-
Summary CV for Academic Supervisor [Professor Robert Jones]	-	-

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

No conflicts of interest were declared in relation to this application

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please

use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WA/0038

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr Derek James Crawford, MBChB, FRCS
Chair

E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy: Sponsor: Mr Hefin Francis
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c/o: Miss Debra Slater
Clinical Academic

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Betsi Cadwaladr University Health Board
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debra.slater@wales.nhs.uk **Wales Research Ethics Committee 5**
Attendance at Committee meeting on 19 February 2015

Committee Members

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr. Karen Addy	Clinical Psychologist	Expert	No
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	No
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	Yes
Mr. Derek James Crawford	Retired Consultant Surgeon (Chair)	Expert	Yes
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	Yes
Ms. Geraldine Jenson	Retired College Vice-Principal	Lay +	Yes
Mr. Eliezer Lichtenstein	Student	Lay +	Yes
Dr. Mark Lord	Consultant Pathologist	Expert	Yes
Dr. Pamela Martin-Forbes	NISCHR Research Officer	Expert	Yes
Dr. Paul Mullins	Reader, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mrs. Rachel Roberts-Jones	Student	Lay +	Yes
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	No
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Vice-Chair)	Expert	Yes
Ms. Sydna Ann Williams	Lecturer	Lay +	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Summary of how issues raised by the Research Ethics Committee have been addressed by the research team

- 1. The research protocol should include a detailed explanation of the methodology employed as well as a justification of the analysis plan. The Committee suggested that the applicants consider presenting the protocol as a pilot study as the outcome measures identified will not adequately answer the research question. A feasibility/pilot study will establish how feasible it is to apply the technique in this group of participants.***

How this has been addressed:

The research protocol has been presented as a pilot study, the outcome of which will inform the feasibility of using auto-photography (taking pictures of valued aspects of life) amongst people with learning disabilities. The outcome will also indicate whether the combination of taking photographs of valued aspects of life and exploring the content with experienced clinicians affects self-reported levels of mood, anxiety, experiential avoidance and life satisfaction.

Section 7 of the research protocol (Design and procedures) now provides a step by step outline of how the proposed multiple baseline single case experimental design methodology would work in practice.

Section 8 of the research protocol (Justification of the data analysis plan) provides a detailed justification of the chosen analysis plan, as requested by the research ethics committee.

- 2. The burden imposed on participants is disproportionate in relation to the direct benefit participants will derive from taking part in the study. The frequency of the text messages to be answered by participants will need to be reconsidered and reduced.***

How this has been addressed:

Participants will be required to respond to the series of 4 text messages every 3 days (e.g. respond on Monday, then Thursday, then Sunday). This will reduce the burden on participants.

- 3. The committee noted the conduct of the research as proposed would raise severe data protection and confidentiality issues; if participants use their own mobile phone and camera, the privacy policy of the web based platform (FireText Service) would need to be considered. The committee suggested that confidentiality issues can be addressed by replacing the use of personal mobile phone; participants should be provided with an inexpensive mobile phone with incorporated camera, registered to the research team not to the individual participant – which would preserve their anonymity and confidentiality.***

How this has been addressed:

A mobile phone with a camera facility has been sourced at a cost of £20 (see research protocol appendix 1). This will address potential confidentiality issues as the mobile phone will be registered to the research team.

- 4. The information sheet does not adequately ensure that individuals understand the information and can make a voluntary informed decision to enrol and to continue to participate. The participant information sheet should list clearly all study procedures (including the psychometric tests), it should explain how quotations will be used, and ensure that if participants are distressed, they are referred to relevant services/healthcare professional not the emergency department. If participants are directed to contact their GP, a GP letter should be issued to outline the study and inform that the patient has consented to take part.***

How this has been addressed:

The participant information sheet now comprises two separate documents:

1) Participant information sheet I: Overview of Research

- This will be sent to participants for consideration alongside family/carers once the 'Expression of Interest/ I'm interested' form has been received by the research team.

2) Participant information sheet: Outline of Study Procedures

- The second participant information sheet provides a step by step account of the research process.
- All study procedures, including psychometric assessments (both before and after the intervention) and outlined within this document.

This also includes information about following the points raised by the research ethics committee:

- Who participants may contact if they became distressed (not the emergency department).
- How quotations may be used
- GP liaison and correspondence (a sample draft GP letter template has been included with this amendment submission).

5. *The summary of the study as it appears in section A6-1 of the REC application was not deemed to be an accurate description of the study and not suitable for publication on the NRES website; the summary of the study would need to be re-written adequately to describe in lay terms the aim of the project and the methodology.*

The summary has been re-written in lay terms to provide an understandable overview of the research aims and methodology. This can be found at the beginning of the research protocol and in section A6-1 of the REC application form. Lay terminology is subsequently adopted throughout the research protocol in order to describe research concepts and rationale more clearly for the reader throughout.

New documents:

- 1) Research protocol – V2. 20.02.15
- 2) Participant information sheet – Overview of the research – V2. 20.02.15
- 3) Participant Information sheet – Outline of the study procedures– V2. 20.02.15
- 4) Draft GP letter template – V2. 20.02.15
- 5) 'Expression of Interest form/ "I'm Interested" Form – V1. 20.02.15 (This will be disseminated alongside the 'Information for recruiting clinicians' form so that it is easily accessible for clinicians when approaching potential participants about the study).
- 6) Updated Consent form to reflect that participants will be provided with a mobile phone for the duration of the research. An additional consent point has been added: *"I understand that I will need to give the mobile phone back to the research team at the end of the study."*
- 7) 'Easy-Read' text message scoring guidelines have been provided as an example of how participants may be helped to rate their levels of mood, anxiety, experiential avoidance and life satisfaction (as referred to in the updated research protocol).
- 8) Privacy and Lost data Policies for Firetext (Automated Text Message Service)

NB. The Information for recruiting clinicians' form has been amended to reflect the fact that participants will not need to use their own mobile phone/camera as this will be provided by the research team.

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.

Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

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Miss Natalie Boulton

Trainee Clinical Psychologist

North Wales Clinical Psychology Programme

43 College Road,

Bangor, Gwynedd

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psp2cd@bangor.ac.uk

23 March 2015

Dear Miss Boulton

Study title: Life through a lens: A pilot study investigating the use of autophotography and self reported levels of anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

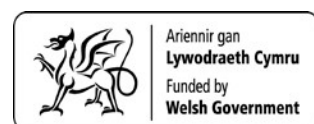
REC reference: 15/WA/0103

IRAS project ID: 178275

The Research Ethics Committee reviewed the above application at the meeting held on 19 March 2015. The committee wishes to thank you and Dr Williams for attending to discuss the application.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to a meeting of the Sub-Committee of the REC.

Further information or clarification required

Protocol

1. The study protocol should be reviewed to account for the three interventions received by participants "text messages", "auto-photography" and "interview"; validate/control for text messages as intervention by collecting data for a number of weeks before and after the "autophotography" intervention.
2. The methodology should include outcome measures relevant to the feasibility nature of the study
e.g. the frequency of photograph, number of photos taken, frequency of response to text message
3. The protocol should detail the pathway for managing incidental disclosures.
4. The protocol should detail the referral pathway for participants which do not benefit from the intervention (intervention has a negative effect or impact on their mood)

Participant Information Sheet and Consent Form

1. The Participant Information Sheet should be amended to reflect changes to the protocol detailed above.
2. Participants should be made aware of what options they have for help if the study has a negative effect on their mood.
3. The Participant Information Sheet needs to be proof-read; spelling mistakes grammatical and typographical errors should be corrected.
4. The Consent Form needs to include a paragraph relating to the limits of confidentiality seeking explicit consent to disclose incidental findings.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Dr Rossela Roberts, RES Manager, at the address in the letterhead.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following

link: <http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisionalopinion/>

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 22 April 2015.

Summary of the discussion at the meeting

Social or scientific value; scientific design and conduct of the study

The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol and concluded that several points highlighted by the Committee in a previous review have been addressed, however, several concerns remain. The Committee noted that the protocol considers the auto-photography as an intervention but overlooks the potential effect of the text messages as an intervention.

If the impact of auto-photography is evaluated then outcome measures such as the frequency of photograph, number of photos taken, frequency of response to text messages need to be collected.

You clarified that each intervention is validated separately. The effect of the text messages is accounted for in the baseline stability methodology; participants receive the text messages for a number of weeks until baseline stability is achieved - and only then they receive the study intervention.

The Committee suggested that obtaining a measure at the end of the “auto-photography” intervention will allow to control for the impact of the “text message” intervention and the “interview” intervention.

You agreed that the text intervention could be administered 6 weeks either side of the autophotography intervention.

The Committee concluded that the protocol needs to acknowledge the potential impact of the text messaging and the interview, either as interventions or as confounding factors and the methodology needs to be adjusted accordingly.

The Committee noted that the study is presented as a pilot investigation but it is not clear what changes in methodology make it a feasibility study; the analysis plan needs to be more rigorous and a general linear model could be applied.

You clarified that a generalisation to the entire population will not be possible, conclusion will be drawn within limits and they will only be relevant to the study sample.

The Committee suggested that a better-defined statistical analysis might improve the chance of this research being accepted for publication. Further information is available in 'Single Subject Research: Strategies for Evaluating Change', Kratochwill, Academic Press 1977, where a number of methods are discussed and referenced. The Committee emphasizes that this is merely a suggestion, and is not a condition of ethics approval.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality

The Committee discussed the arrangements made to protect privacy through confidentiality as well as the information governance aspects of the study, where and for how long will data be stored, and clarified who will have access to the data.

The Committee queried the procedure to deal with incidental disclosures (sub-optimal care, malpractice or abuse, risk to self and others) and the statutory requirement to break confidentiality and requested that this is elaborated in the protocol.

Favourable risk benefit ratio; anticipated benefit/risks for research participants

The Committee discussed the anticipated benefits and potential risks to participants and was satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants.

The Committee noted that the potential risk and burden have been significantly reduced in the revised protocol but requested a clarification of the process in place to address the fact that participants may not derive a benefit from the study – a written protocol needs to be in place. You clarified that if the study intervention makes a participant feel worse, this would become clear throughout the study in the responses given to the text message; in this case the participant will be directed to the clinical care team and the care coordinator who will consider whether the participant should be withdrawn from the study; participants who feel that the study does not benefit them can withdraw from the study at any time.

It was also noted the protocol still mentions that participants who experience distress should report to Emergency Department. You agreed to review the protocol for accuracy.

Informed Consent process and the adequacy and completeness of participant information

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but felt that minor amendments should be made to ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate. The Consent Form needs to include a paragraph relating to the limits of confidentiality seeking explicit consent to disclose incidental findings.

Other general comments missing information/ typographical errors/ application errors/ The Participant Information Sheet needs to be proof-read; spelling mistakes grammatical and typographical errors should be corrected.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting

Based on the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value;
- Recruitment arrangements and access to health information, and fair participant selection

- Informed consent process and the
- Suitability of the applicant and supporting staff
- Independent review
- Suitability of supporting information
- Other general issues
- Suitability of the summary of the research

The Committee identified issues with the following aspects of the research:

- Scientific design and conduct of the study
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity • Adequacy and completeness of participant information

Documents reviewed

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC Application Form [REC_Form_05032015]	-	05 March 2015
Covering letter on headed paper [Summary document outlining how points raised by the Research Ethics Committee have been addressed]	-	20 February 2015
Other [Unfavourable opinion letter at previous review]		20 February 2015
Research protocol or project proposal [Research Protocol]	2	20 February 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Visual representation & further explanation of proposed multiple baseline single case experimental design methodology]	1	20 January 2015

Other [Email correspondence with FireText Marketing Manager - Automated Text Message Service Privacy & Lost Data Policies]	-	26 February 2015
GP/consultant information sheets or letters [Clinician Information Sheet]	2	20 February 2015
Participant information sheet (PIS) [Participant Information Sheet I - Overview of Research]	1	20 February 2015
Participant information sheet (PIS) [Participant Information Sheet II – Overview of study procedures]	2	20 February 2015
Other [Expression of Interest Form for Recruiting Clinicians]	1	20 February 2015
Letters of invitation to participant [Opt in /Tell me More form]	2	20 February 2015
Participant consent form [Consent Form]	2	20 February 2015
GP/consultant information sheets or letters [Example GP Letter Template]	1	20 February 2015
Other [Easy Read Text Message Scoring Guidance]	1	20 February 2015
Summary CV for Chief Investigator [Miss Natalie Boulton]		20 January 2015
Summary CV Academic Supervisor [Professor Robert Jones]	-	20 January 2015
Evidence of Sponsor insurance or indemnity [UMAL insurance certificate Bangor University]	-	01 August 2014

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

No conflicts of interest were declared in relation to this application.


Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/WA/0103

Please quote this number on all correspondence

Yours sincerely



Mr Derek James Crawford, MBChB, FRCS

Chair

E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy: Sponsor:

Mr Hefin Francis

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R&D Office: Dr Nefyn Williams

c/o: Miss Debra Slater
Clinical Academic

Office

Ysbyty Gwynedd Hospital

Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW debra.slater@wales.nhs.uk **Wales**

Research Ethics Committee 5

Attendance at Committee meeting on 19 March 2015

Committee Members

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No
Mr. Derek James Crawford	Retired Consultant Surgeon (Chair)	Expert	Yes
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	Yes
Ms. Geraldine Jenson	Retired College Vice-Principal	Lay +	Yes
Mr. Eliezer Lichtenstein	Student	Lay +	Yes
Dr. Mark Lord	Consultant Pathologist	Expert	Yes
Dr. Pamela Martin-Forbes	NISCHR Research Officer	Expert	Yes

Dr. Paul Mullins	Reader, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mrs. Rachel Roberts-Jones	Student	Lay +	Yes
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Vice-Chair)	Expert	Yes
Ms. Sydna Ann Williams	Lecturer	Lay +	No

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Response to request for further information from REC

Summary of how the points raised by the Research Ethics Committee have been addressed by the research team

Protocol

1. The study protocol should be reviewed to account for the three interventions received by participants “text messages,” “auto-photography” and “interview;” validate/control for text messages as intervention by collecting data for a number of weeks before and after the “auto-photography” intervention.

How this has been addressed:

The protocol has been reviewed to account for the phases of the current feasibility study in the following way:

i) Page 7

Section 7: Stage 4 is now referred to as the “*Text message phase*” within the protocol. During this phase, participants will be required to respond to a series of text messages rating their mood, anxiety, life satisfaction and experiential avoidance by text message only.

In order to account for the potential impact of receiving text messages, participants will receive and reply to the series of text messages for two weeks. Following this two-week familiarisation phase, the intervention (sessions with clinician and taking photos of valued aspects of life) will begin once baseline stability has been achieved for each participant.

ii) Page 7

Section 7 (Design & Procedures), Stage 5: “Auto-photography intervention” has been explained in a way which clarifies that the taking photographs of valued aspects of life forms part of the ACT intervention that participants will receive, as opposed to two independent components. An additional paragraph has been added to **Page 2: Section 4 “Background, 4.1 Acceptance and Commitment Therapy”** in order to provide some context regarding the current status of psychological therapy for people with learning disabilities (which are often cognitive or linguistically based) and the need for adaptations of existing approaches in order to enhance meaningful accessibility for people with learning disabilities.

iii) Page 8

Section 7 (Design and Procedures) Stage 6: “Post Intervention”

A paragraph has been added to explain that data collection via text message (in the form of the same series of 4 text messages, every 3 days) will take place for two weeks following collection of the final data point from each participant, prior to the follow-up session where psychometric assessments measures will be repeated.

2. The methodology should include outcome measures relevant to the feasibility nature of the study e.g. the frequency of photograph, number of photos taken, frequency of response to text messages.

Page 8

Section 7 (Design and Procedures) Stage 7: “Outcome measures relevant to the feasibility nature of the study”

This section includes an outline of the outcome measures relevant to the feasibility nature of the study. These include: i) the number of photographs taken between sessions with clinician; ii) frequency of text message replies and iii) frequency of attendance for individual sessions with clinicians.

3. The protocol should detail the pathway for making incidental disclosures

Page 13

Section 15: “Pathway for incidental disclosures”

The pathway for potential incidental disclosures is outlined here.

4. The protocol should detail the referral pathway for participants which do not benefit from the intervention (intervention has a negative effect or impact on their mood).

Page 13

Section 16: “Referral pathway for participants who may not benefit from the intervention (the intervention has a negative impact on their mood)”

This section now outlines the referral pathway for participants who may not benefit from the intervention (the intervention has a negative effect or impact on their mood).

Participant Information Sheet and Consent Form

1. The Participant Information Sheet should be amended to reflect changes to the protocol detailed above.

Participant Information Sheet II has been amended to reflect:

- i) That text message replies will be collated for at least two weeks pre-intervention and a further two weeks post-intervention
- ii) That data pertaining to frequency of photographs, attendance and text message replies will be collated
- iii) The nature of the referral pathway for incidental disclosures and the need to break confidentiality if this became apparent.

2. Participants should be made aware of what options they have for help if the study has a negative effect on their mood.

Participant Information Sheet II now clarifies that participants do not need to continue their involvement in the research if their mood is negatively impacted (and the referral pathway for such cases) in the section entitled “What happens if I get upset because of taking photographs or sending messages about how I feel or if it makes me feel worse?” (Page 4).

3. The participant information sheet needs to be proof-read; spelling mistakes grammatical and typographical errors should be corrected.

All documents have been proof read and errors amended.

4. The consent form needs to include a paragraph relating to the limits of confidentiality seeking explicit consent to disclose incidental findings.

Two additional items have been added to the consent form seeking explicit consent from participants that confidentiality may be broken in instances where incidental disclosures become apparent (Points 11 & 12).

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
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Miss Natalie Boulton

Trainee Clinical Psychologist

North Wales Clinical Psychology Programme

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psp2cd@bangor.ac.uk

01 June

2015 Dear Miss Boulton,

Study title: Life through a lens: A pilot study investigating the use of auto-photography and self reported levels of anxiety amongst people with learning disabilities, a multiple baseline single case experimental design.

REC reference: 15/WA/0103

IRAS project ID: 178275

Thank you for your letter of 28 May 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a Sub-Committee of the REC held on 1 June 2015. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Dr Rossela Roberts, rossela.roberts@wales.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC Application Form [REC_Form_05032015]	-	05 March 2015
Covering letter on headed paper [Summary document outlining how points raised by the Research Ethics Committee have been addressed]	-	20 February 2015
Research protocol or project proposal [Research Protocol]	3	09 April 2015
Letters of invitation to participant [Tell me More form]	2	20 February 2015
Participant information sheet [Overview of Research]	3	19 May 2015
Participant Information Sheet [Outline of study procedures]	3	19 May 2015
Participant consent form [Consent Form]	3	19 May 2015
GP/consultant information sheets or letters [Information Sheet]	2	20 February 2015
Other [Expression of Interest Form for Recruiting Clinicians]	1	20 February 2015
Other [Email correspondence with FireText Marketing Manager]	-	26 February 2015
Other [Easy Read Text Message Scoring Guidance]	1	20 February 2015
Summary, synopsis or diagram of protocol in non technical language	1	20 January 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	-	01 August 2014
Summary CV for Chief Investigator [Miss Natalie Boulton]	-	20 January 2015
Summary CV for supervisor [Professor Robert Jones]	-	20 January 2015
Other [Response to request for further information]	1	19 May 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WA/0103

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely




Dr Philip White, MBChB, FRCGP
Chair

E-mail: rossela.roberts@wales.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*



“After ethical review – guidance for researchers” SL-AR2 After ethical review - research oth

Copy: Sponsor: Mr Hefin Francis
School of Psychology, Bangor University,
Brigantia Building, Penrallt Road,
Bangor, Gwynedd, LL57 2AS h.francis@bangor.ac.uk

Academic Supervisor: Prof Robert Jones
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R&D Office: Dr Nefyn Williams
c/o: Miss Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW debra.slater@wales.nhs.uk **Wales**
Research Ethics Committee 5

Attendance at Sub-Committee of the REC meeting on 1 June 2015

Committee Members

Name	Profession	Capacity	Present
Dr. Paul Mullins	Reader, MRI Physicist	Lay +	Yes

Dr. Jason Walker	Consultant Anaesthetist (Vice-Chair)	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Chair)	Expert	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Appendix C – Application for NHS Research & Development (R&D) Approval

NHS Site-Specific Information Form (NHS sites)

R&D Initial Opinion Letter

Response to request for further information

Confirmation of R& D approval

NHS R&D Approval conditions

Notification of minor amendment

Minor amendment approval

Appendix C: Initial R & D Opinion Letter

From: Debra Slater (BCUHB - Research & Development) <Debra.Slater@wales.nhs.uk>
Sent: 19 May 2015 11:10
To: Natalie Elizabeth Boulton
Cc: Robert Jones; Hefin Francis; Jonathan Williams (BCUHB - Learning Disabilities)
Subject: Life through a lens (IRAS ID 178275) - IRP Comments: response required

Dear Miss Natalie Boulton

Re: BCUHB R&D – request for information/clarification - response required

Study Title	Auto-photography & Anxiety among people with a learning disability: Life through a lens
IRAS reference	178275

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel (IRP) on **14th May 2015**.

The IRP discussed the research governance issues arising under the following checks:

Compliance with Data Protection Act and data security issues assessed

The Panel discussed the information governance aspects of the study, specifically relating to adherence with UK law and Health Board policies. The Panel seek clarification that the mobiles being used, internet access will be disabled. The Panel further discussed the safety of photos on the device and would like confirmation how this will be ensured.

Participant information & consent documents and process

The Panel considered the proposed consent process to ensure that any legal implications presented by the study are highlighted and considered the accuracy of the information provided. The Panel noted that the study name was missing from the header of both the participant information sheet and consent form. The Panel queried if the participant will understand sufficiently the need to ask for permission to take a photo (of a person) and recommend this to be explained more clearly on the participant information sheet, and explained further when consenting the participant.

Before confirming its final opinion the Panel asked for a complete response to the issues identified in the following governance checks:

Compliance with Data Protection Act and data security issues assessed

The Panel request clarification that the mobile phone internet access will be disabled and assurance around the safety of photos on the device.

Participant information & consent documents and process

The Panel recommend adding the study title to the header of both the participant information sheet and consent form. The Panel recommend adding further clarification around seeking permission to take a photo (of

a person) to the participant information sheet and should be explained further when taking participant consent.

Authority to consider the further information and to confirm the Panel's final opinion has been delegated to the Chairman.

If you would like further information on any other points covered by this letter please do not hesitate to contact me directly. A response should be returned within 14 days of this notification email.

Kind regards

Debra Slater

Research Governance Officer
Betsi Cadwaladr University Health Board (BCUHB)
01248 384877 / 01352 71838

Study Title: Auto-photography & Anxiety among people with a learning disability: Life through a lens

IRAS Reference: 178275

Response to request for information/clarification from BCUHB R&D regarding:

Please find below a complete response to the issues identified during discussion of the above project at the BCUHB R&D Internal Review Panel on 14th May 2015:

i) Compliance with Data protection Act and data security issues assessed:

The panel request clarification that the mobile phone internet access will be disabled and assurance around the safety of photos on the device.

How this has been addressed by the researchers:

Appendices 1 & 2 depict a transcript of a web-conversation with Tesco Mobile regarding their 'SIM-only' packages. This confirms that, not only will internet access be disabled on the mobile phone, but the SIM card will allow text messages only, no internet data or GPRS which would enable internet access. As outlined in the transcript, the mobile phone would also be **unable** to access wi-fi. Thus removing the potential of photographs being inadvertently uploaded to the internet through automatic web-based packages (e.g. Facebook/Google)

ii) Participant information and consent documents and process

The panel recommend adding the study title to the header of both the participant information and consent form. The panel recommend adding further clarification around seeking permission to take a photo (of a person) to the participant information sheet and should be explained further when taking participant consent.

How this has been addressed by the researchers:

- The study title has been added to the header of participant information sheets I and II and consent form.
-
- Further clarification has been provided around seeking permission to take a photo. This will be further reinforced during the initial assessment phase where the researcher will practice a short role play with the participant (and supporter) whereby the participant will practice asking to take a photo and responding to both 'yes' and 'no' responses. This will help to ensure that i) the participant has the cognitive verbal skills to ask permission to take a photo. ii) Encourage generalisation of skills and enhance their ability to practice this in real life settings.

Item 9 on the consent form now contains the following sentence in order to further explain what is required of them, during the consent process:

"I know that I need to ask people if it is OK before I take a photo of them and not to take a photo if they don't want me to. I can do this by saying "Is it OK if I take a photo of you?""

Further clarification has also been provided in participant information sheet II. This has been done through the addition of the following sentences:

"We would practice asking people if it was OK to take a photo of people."

"If you wanted to take a picture of people you know, you would need to check that this was OK with them first (and only take the picture if they say 'Yes')."

Appendix 1: Transcript of conversation with a Tesco Mobile Advisor re. disabling internet access on mobile phones (19th May 2015).



Tesco Mobile LiveChat <noreply@tescomobile.com>

Tue 19/05/2015 14:12

Mark as unread

To: ■ Natalie Elizabeth Boulton;

Please find a copy of your chat content below.

General Info	
Chat start time	May 19, 2015 8:28:54 AM EST
Chat end time	May 19, 2015 9:12:38 AM EST
Duration (actual chatting time)	00:43:44
Operator	Patricia

Chat Transcript
<p>info: Welcome to Tesco Mobile live chat. Someone will start chatting with you soon.</p> <p>info: You're through to Patricia.</p> <p>Patricia: Hi I'm Patricia. How can I help?</p> <p>Natalie: Hi there I have a query about sim only please</p> <p>Natalie: I wondered whether there is an option to purchase a sim card which does not have any internet access / data? I want the phone just for text messages you see</p> <p>Natalie: it's for a research project where participants are unable to access the internet so I'd need to make sure internet was disabled</p> <p>Patricia: In this case I would suggest you that simply buy a pay as you go SIM and buy a text bundle and start using it without any hassle.</p> <p>Natalie: Oh great so is this an option? I presumed that the sim cards came with data included in the 'bundle' ?</p> <p>Patricia: Let me help you with pay as you go bundles:</p> <p>Patricia: 1. £5= 150 minutes</p> <p>Patricia: 2. £5= 5000 texts</p> <p>Patricia: 3. £5= 500 MB</p> <p>Patricia: 1GB Data £7.50 1 month</p> <p>2GB Data £10.00 1 month</p> <p>3GB Data £12.50 1 month</p> <p>4GB Data £15.00 1 month</p> <p>6GB Data £17.50 1 month</p> <p>8GB Data £20.00 1 month</p> <p>Natalie: Excellent. This is very helpful, thank you. So may I just confirm to make sure - if I bought a mobile phone from Tesco mobile on pay as you go, I would then simply need to purchase the option 2 that you have listed above (£5 for 5000 texts). Please also confirm that there is no time limit on when the texts need to be used by - i.e. that I wouldn't need to top up £5 every month for example?</p> <p>Patricia: Let me explain you pay as you go tariffs as well:</p> <p>Patricia: Triple Credit - Top-Up with £10 and get £30 credit. Call rates are 25p/minutes for calls and 10p/text for texts.</p> <p>Patricia: Lite Tariff - Top-Up with £10 and get £10 credit. Call rates are 8p/minutes for calls and 4p/text for texts.</p> <p>Patricia: The minimum top-up amount is £10</p> <p>Patricia: Real credit will never expire until you can use it you simply need to make only 1 chargeable call within 6 months to remain your SIM active always.</p> <p>Natalie: Oh Ok, I see. So I'd need to top up £10 initially when I buy the phone. And then could add £5 top up which would be for Text only and NO internet access whatsoever?</p> <p>Patricia: You can simply top-up your phone by £10 after that you can simply call on 2709 free from your phone and our team will add £5= 5000 texts +£5= 500 MB of data for you in your account.</p> <p>Natalie: Excellent. Thanks once again. So just for my reassurance, can I confirm that if I do as you suggested above, the mobile phone will NOT be able to access any internet functions at all (even if the apps are pre-programmed into the mobile phone). Many thanks again.</p> <p>Patricia: You can also use Internet with the help of Wi-Fi in your phone free of cost.</p> <p>Natalie: Is there a way that this can be disabled on the mobile phone do you know?</p> <p>Patricia: Do you want to stop GPRS in your handset?</p> <p>Natalie: Yes. I'd need the phone to have no access to internet whatsoever.</p> <p>Patricia: Sure once you will buy your new phone simply not add any data bundle in your phone.</p> <p>Natalie: this is great, thank you. So the phone only has internet access when a data bundle is added? As long as I don't purchase a data bundle, the phone will not have internet access (even on wi-fi) ?</p> <p>Patricia: Please do not worry at all once you will buy a phone simply switch off Wi-Fi and mobile data in your phone after that Internet will not work at all in your handset.</p> <p>Natalie: Thanks very much for your help. That's all I needed confirmation of. Thanks, Natalie</p> <p>info: We'll email a copy of your chat transcript to psp2cd@bangor.ac.uk.</p> <p>Patricia: My pleasure, Natalie.</p> <p>Patricia: I'm happy that I could help you today. It was nice chatting with you.</p> <p>Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.</p> <p>Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.</p> <p>Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.</p>

In the event that the text is unclear in the 'screenshot's' above, please find a copy and pasted text version below which provides clarity regarding the conversation:

Appendix 2: 'Copy and paste' Text version of conversation with Tesco Mobile re. disabling internet access (provided for clarity if text is unclear on 'screenshot' images of actual conversation)

Please find a copy of your chat content below.

General Info	
Chat start time	May 19, 2015 8:28:54 AM EST
Chat end time	May 19, 2015 9:12:38 AM EST
Duration (actual chatting time)	00:43:44
Operator	Patricia

Chat Transcript
<p>info: Welcome to Tesco Mobile live chat. Someone will start chatting with you soon.</p> <p>info: You're through to Patricia.</p> <p>Patricia: Hi I'm Patricia. How can I help?</p> <p>Natalie: Hi there I have a query about sim only please</p> <p>Natalie: I wondered whether there is an option to purchase a sim card which does not have any internet access / data? I want the phone just for text messages you see</p> <p>Natalie: it's for a research project where participants are unable to access the internet so I'd need to make sure internet was disabled</p> <p>Patricia: In this case I would suggest you that simply buy a pay as you go SIM and buy a text bundle and start using it without any hassle.</p> <p>Natalie: Oh great so is this an option? I presumed that the sim cards came with data included in the 'bundle' ?</p> <p>Patricia: Let me help you with pay as you go bundles:</p> <p>Patricia: 1. £5= 150 minutes</p> <p>Patricia: 2. £5= 5000 texts</p> <p>Patricia: 3. £5= 500 MB</p> <p>Patricia: 1GB Data £7.50 1 month</p> <p>2GB Data £10.00 1 month</p> <p>3GB Data £12.50 1 month</p> <p>4GB Data £15.00 1 month</p> <p>6GB Data £17.50 1 month</p> <p>8GB Data £20.00 1 month</p> <p>Natalie: Excellent. This is very helpful, thank you. So may I just confirm to make sure - if I bought a mobile phone from Tesco mobile on pay as you go, I would then simply need to purchase the option 2 that you have listed above (£5 for 5000 texts). Please also confirm that there is no time limit on when the texts need to be used by - i.e. that I wouldn't need to top up</p>

£5 every month for example?

Patricia: Let me explain you pay as you go tariff's as well:

Patricia: Triple Credit - Top-Up with £10 and get £30 credit. Call rates are 25p/minutes for calls and 10p/text for texts.

Lite Tariff - Top-Up with £10 and get £10 credit. Call rates are 8p/minutes for calls and 4p/text for texts.

Patricia: The minimum top-up amount is £10

Patricia: Real credit will never expire until you can use it you simply need to make only 1 chargeable call within 6 months to remain your SIM active always.

Natalie: Oh Ok, I see. So I'd need to top up £10 initially when I buy the phone. And then could add £5 top up which would be for Text only and NO internet access whatsoever?

Patricia: You can simply top-up your phone by £10 after that you can simply call on 2709 free from your phone and our team will add £5= 5000 texts +£5= 500 MB of data for you in your account.

Natalie: Excellent. Thanks once again. So just for my reassurance, can I confirm that if I do as you suggested above, the mobile phone will NOT be able to access any internet functions at all (even if the apps are pre-programmed into the mobile phone). Many thanks again.

Patricia: You can also use Internet with the help of Wi-Fi in your phone free of cost.

Natalie: Is there a way that this can be disabled on the mobile phone do you know?

Patricia: Do you want to stop GPRS in your handset?

Natalie: Yes. I'd need the phone to have no access to internet whatsoever.

Patricia: Sure once you will buy your new phone simply not add any data bundle in your phone.

Natalie: this is great, thank you. So the phone only has internet access when a data bundle is added? As long as I don't purchase a data bundle, the phone will not have internet access (even on wi-fi) ?

Patricia: Please do not worry at all once you will buy a phone simply switch off Wi-Fi and mobile data in your phone after that Internet will not work at all in your handset.

Natalie: Thanks very much for your help. That's all I needed confirmation of. Thanks, Natalie
info: We'll email a copy of your chat transcript to psp2cd@bangor.ac.uk.

Patricia: My pleasure, Natalie.

Patricia: I'm happy that I could help you today. It was nice chatting with you.

Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.

Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.

Patricia: We'd really like your feedback. Click on 'Close chat' in the top right of this screen to tell us what you think. Bye.



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D - Canolog R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Natalie Boulton Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP North Wales Clinical Psychology

Programme Email: rossela.roberts@wales.nhs.uk

43 College Road

Bangor

LL57 2AS

debra.slater@wales.nhs.uk

sion.lewis@wales.nhs.uk

Tel/Fax: 01248 384 877

psp2cd@bangor.ac.uk

21st May 2015

Dear Miss Boulton

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title Autophotography & anxiety among people with a learning disability: Life through a lens

IRAS reference 178275

REC reference 15/WA/0103

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

Thank you for responding to the Panel's request for further information. The R&D office considered the response on behalf of the Panel and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board (BCUHB) sites as described in the application.

The documents reviewed and approved are listed below:

Documents:	Version:	Date:
R&D form	V4.0.0	20/04/2015
SSI form	V4.0.0	20/04/2015
Protocol	V3	09/04/2015
Visual representation of proposed research design (graph)	V1	20/01/2015
Participant Information Sheet (I)	V3	19/05/2015
Participant Information Sheet (II)	V4	19/05/2015
Participant Information Sheet (Clinicians)	V2	20/02/2015

Consent	V4	19/05/2015
Opt-In form (tell me more)	V2	20/02/2015
Expressions of Interest form	V1	20/02/2015
Guidelines for functional assessment of capacity	V1	20/01/2015
GP Letter Template	V1	20/02/2015
Easy read SMS text message scoring	V1	20/02/2015
Summary CV: Boulton	V1	20/01/2015
Summary CV: Jones	V1	20/01/2015
Summary CV: Williams	V1	20/04/2015
Evidence of Insurance		Expires 31/07/2015
Risk Assessment completed		20/04/2015
Documents:	Version:	Date:
Correspondence: "Firetext" – Privacy/Lost data Policy		27/02/2015
REC Provisional Opinion Letter		23/03/2015
Correspondence letter to REC: response to request for further information	V1	09/04/2015

All research conducted at the Betsi Cadwaladr University Health Board (BCUHB) sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crnc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP

Associate Director of R&D
Chairman Internal Review
Panel

Copy to:

Sponsor:

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Academic Supervisor:

Professor Robert Jones

School of Psychology

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Bangor

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r.s.jones@bangor.ac.uk

RESEARCH IN HUMAN SUBJECTS

OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

Standard conditions of approval by the BCUHB - R&D Internal Review Panel

Further communications with the Internal Review Panel (IRP)

Further communications during the research with the IRP that gave R&D Approval (hereafter referred to in this document as “the Panel”) are the personal responsibility of the Chief Investigator (CI) or Principal Investigator (PI) for the site. However, the sponsor may delegate responsibility to the CI or another representative.

Commencement of the research

It is assumed that the research will commence (i.e. the initiation of any protocol procedures) within 12 months of the date of the approval.

Should the research not commence within 12 months, the Sponsor should give the Panel a written explanation for the delay. It is open to the Panel to allow a further period of 12 months within which the research must commence.

Should the research not commence within 24 months, the Panel may review its opinion.

Training and Standard Operating Procedures (SOPs)

It is the responsibility of the staff involved in research studies to undertake their GCP training.

It is also the responsibility of the staff to register and successfully complete assessment tests on relevant SOPs that they would be required to know to undertake their research project. These SOPs are arranged on the quality system website according to the stage of researcher, and the role of the researcher. Web links will take the researcher to a multiple choice question test that is specific to that researcher's role and the stage of the research project.

To access the SOPs via NHS eLearning, go to <http://learning.wales.nhs.uk/>. If you do not have a BCUHB, Bangor or Glyndwr University email address contact Lona.TudorJones@wales.nhs.uk to authorise access.

Adherence to all training requirements will be subject to audit.

Duration of approval

The approval generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Panel should be notified.

Progress reports

The Panel is required to keep the approval under review in the light of progress reports and any developments in the study. The CI or PI submit a progress report to the Panel every 6 months after the date on which the approval was given

Progress reports should be in the format prescribed by the Panel. An electronic version is available from the R&D office. The Panel should be kept informed of any significant findings or recommendations by an Independent Data Monitoring Committee or equivalent body established for the study.

The R&D Office will send a reminder to the CI or PI when the progress report is due. If the progress report is not received within one month the Panel will notify the Sponsor. Failure to submit the progress report following these steps will result in suspension of the R&D approval for this project.

The CI or PI may be requested to attend a meeting of the Panel to discuss the progress of the research.

Monitoring and Auditing

BCUHB/BU are responsible for auditing research practice and assuring adherence to current legislation and guidelines. As such, it is necessary to audit research for which BCUHB/BU is the lead Sponsor and for high risk hosted research studies, against the standards of the Research Governance Framework 2009 and Amended Medicines for Human Use (Clinical Trials) Regulations 2004, where applicable and against the quality system of Good Clinical Practice intrinsic to the Regulations including adherence to all other applicable regulations (e.g. IRM(E)R, HTA, MCA etc.)

An audit could consist of a complete overview of one study, a specific study procedure/process or system. The audit timetable will consist of a rolling programme of routine audits. Audit may also be triggered if an issue of concern has been highlighted with a specific study or study procedure/system, or if documented evidence is required on a particular issue.

Amendments

If the sponsor proposes to make a substantial amendment to the research, a Notice of Amendment form should be submitted to the Panel, after the REC and MHRA have confirmed approval.

A substantial amendment is any amendment to the terms of the application for review, or to the protocol or other supporting documentation approved by the Panel that is likely to affect to a significant degree the safety or physical or mental integrity of the research participants, the scientific value of the research or the conduct or management of the research.

Notices of amendment should be in the format prescribed by NRES and published on the website, and should be signed by the CI or Sponsor.

A substantial amendment should not be implemented until approval has been given by the IRP and a favourable ethical opinion has been issued by the Ethics Committee, unless the changes to the research are urgent safety measures.

Urgent safety measures

The sponsor, CI or PI at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

The Panel must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

Adverse Events

The Chief Investigator (or PI as applicable) is responsible for the recording of adverse events and adequate reporting in accordance to the regulatory requirements and BCUHB policies.

Conclusion or early termination of the research

The sponsor or CI should notify the Panel in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

If the research is terminated early, the CI should notify the Panel within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

Reports of conclusion or early termination should be submitted in the form prescribed by the Panel

Final report

The sponsor or CI should provide the Panel with a summary of the final report on the research should be provided to the Panel within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

Review of approval

The Panel may review its opinion at any time in the light of any relevant information it receives.

The Sponsor, CI or PI may at any time request that the Panel reviews its opinion, or seek advice from the Panel on any issue relating to the research.

Serious breaches of Good Clinical Practice or the protocol

The Panel should be promptly notified of any serious breach of the conditions or principles of Good Clinical Practice (GCP) or of the protocol. A breach should be regarded as serious if it is likely to affect to a significant degree the safety or physical or mental integrity of the subjects of the study, or the scientific value of the study. The sponsor should notify the Panel, the REC in writing within 7 days of the matter coming to their attention. There is no requirement to notify minor breaches of GCP or the protocol.

A minor deviation from the protocol to deal with unforeseen circumstances is not considered to be a serious breach of the protocol provided that it is approved by the CI, either in advance or after the event. However, if the deviation would meet the criteria for a substantial amendment it should be notified to the Panel.

There is no statutory provision for the Panel to approve proposed deviations from the protocol for individual subjects. It is the responsibility of the sponsor to consider whether protocol amendments should be made in such cases. Where the amendment is substantial, it should be notified.

Breach of approval conditions

These approval conditions set out important guidance which sponsors, CIs and PIs are expected to follow. Failure to comply with these conditions may lead to a change of the Panel's opinion and a recommendation that approval by the Panel should be suspended or terminated.

Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.

If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

Instructions for using this template

- For guidance on amendments refer to <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/>
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/>. If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

1. Study Information

Full title of study:	Auto-photography and Anxiety among people with a learning disability
IRAS Project ID:	178275
Sponsor Amendment Notification number:	1
Sponsor Amendment Notification date:	20.11.15
Details of Chief Investigator:	
Name [first name and surname]	Natalie Boulton
Address:	<div>██████████</div> <div>██████████</div> <div>██████████</div> <div>██████████</div>

Postcode:	
Contact telephone number:	██████████
Email address:	Psp2cd@bangor.ac.uk
Details of Lead Sponsor:	
Name:	Bangor University (Hefin Francis)
Contact email address:	h.francis@bangor.ac.uk
Details of Lead Nation:	
Name of lead nation <i>delete as appropriate</i>	Wales
If England led is the study going through CSP? <i>delete as appropriate</i>	Not applicable
Name of lead R&D office:	Betsi Cadwaladr University Health Board (BCUHB)

2. Summary of amendment(s)

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.

If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

No.	Brief description of amendment <i>(please enter each separate amendment in a new row)</i>	Amendment applies to <i>(delete/ list as appropriate)</i>		List relevant supporting document(s), including version numbers <i>(please ensure all referenced supporting documents are submitted with this form)</i>		R&D category of amendment <i>(category A, B, C)</i> <i>For office use only</i>
		Nation	Sites	Document	Version	
1	Change of address for Denbighshire Complex Needs Team. Previously: B7, Trem Y Dyffryn, Colomendy Industrial Estate, Denbigh, Denbighshire, LL16 5TX NEW ADDRESS: Denbighshire County Council, Wynnstay Road, Ruthin, LL15 1YN	England	All sites or list affected sites	Not applicable.	Not applicable.	
		Northern Ireland	All sites or list affected sites			
		Scotland	All sites or list affected sites			
		Wales	All sites or list affected sites			
2	Recruitment to take place across two additional Community Learning Disability teams within North	Wales		Not applicable	Not applicable	

	<p>Wales (all part of Betsi Cadwaladr University Health Board)</p> <p>Additional Sites:</p> <p>Flintshire Community Learning Disability Team</p> <p>Social Services,</p> <p>Entrance 3, 6th Floor,</p> <p>County Hall,</p> <p>Mold, CH7 6NN</p> <p>Anglesey Adult Learning Disability Team</p> <p>Swyddfa Cyngor Mon</p> <p>Llangefni</p> <p>Ynys Mon, LL77 7TW</p> <p>North Gwynedd Learning Disability Team</p> <p>Swyddfa Cyngor Arfon</p> <p>Penrallt, Caernarfon</p> <p>Gwynedd, LL55 1BN</p>				
3					
4					
5					

[Add further rows as required]

3. Declaration(s)

Declaration by Chief Investigator

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator: N.Boulton

Print name: Natalie Boulton

Date: 20.11.15

Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)

The sponsor of an approved study is responsible for all amendments made during its conduct.

The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative:

Print name:.....

Post:

Organisation:.....

Date:.....

Appendix D - Information for Recruiting Clinicians

Information for Clinicians

Life through a lens: Auto-photography and anxiety amongst people with learning disabilities



Do you know a service user that experiences anxiety?

If so, they may be eligible to take part in our research study.

Why is the research being carried out?

In the past, many researchers have used traditional talking therapies to try to help people with learning disabilities to manage their anxiety. Until recently, there has been no research into how taking photographs of valuable items or aspects of life may affect their levels of anxiety.

What are the study aims?

The aim of our study is to see whether taking photographs of things that are important in life and talking about them with a clinician affects self-reported levels of mood, anxiety, experiential avoidance and life satisfaction amongst people with a learning disability.

The study will form part of a Doctorate of Clinical Psychology thesis for Natalie Boulton, who is studying at Bangor University. She is being supervised by Dr Jonathan Williams who is a Senior Clinical Psychologist working at Denbighshire Disabilities Team and Professor Robert Jones who is a Consultant Clinical Psychologist and Programme Director of the North Wales Clinical Psychology Course.

What would be expected of me?

Your help in recruiting participants who experience anxiety would be extremely valuable.

This would involve mentioning the research to people that you work with who may like to be involved. If they are interested, you would provide them with an Expression of Interest form that will be returned to the research team who will then make contact with the service user to explain more about the study.

How would I know if a service user I'm working with may be suitable?

Service users may be considered eligible for inclusion if the answers are 'yes' to the following questions:

- Does the client have a learning disability?
- Are they 18 years old or over?
- Do they experience significant anxiety?
- Can they consent to participate in research?
- Are they familiar with the process of sending and receiving text messages?

Is there anyone that wouldn't be suitable?

If the person that you are thinking of referring is experiencing acute psychosis, active suicidal ideation or attempts, current self harm behaviours, significant mental health difficulties that may be exacerbated by the research **or** if they are unwilling to take part, they would not be eligible for inclusion in the current research.

What do I need to do?

If you know someone who may be interested, simply complete the 'I'm interested' form (attached to this leaflet) with the service user and return to the research team in the stamped addressed envelope that is included in this information pack.

What if I have questions about the study?



If you have any questions you can email or ask someone to e-mail Natalie. Her e-mail address is **psp2cd@bangor.ac.uk**

Complaints

If you have any complaints about this research, please contact:

For an NHS complaint:

Concerns Team

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Bangor
Gwynedd
LL57 2PW
Email: ConcernsTeam.bcu@wales.nhs.uk
Tel: 01248 384194

For a University Complaint: Hefin Francis (School Manager)

School of Psychology
Adeilad Brigantia
Penrallt Road
Gwynedd LL57 2AS
Email: h.francis@bangor.ac.uk
Tel: 01248 388339

Appendix E. Expression of Interest Form



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"I'm Interested" Form

I would like to find out more about the research

Please get in touch to tell me more



Name:.....

Address:

.....

.....



Email address:



Telephone Number:



Signed:



Date:

Appendix F – Participant Information Sheet I (Overview of Research)

Participant Information Sheet I

What is the Research About?

About Me

My name is Natalie Boulton. I'm doing some research and would like to ask for your help.



What is research?

Research is finding out about things in an organised way.

Why have I been asked to take part?

You have been asked to take part because you have had some support from the learning disabilities team before and have had some difficulties managing your worries.

What is the research about?

My research will see if taking photographs of things that are special in your life and talking about them helps you to feel better.

I would like to find out more by sending you text messages to see how you are doing each day.

I will ask you questions about:

- How you feel
- How worried you are
- How scared you are
- How happy you are with your life



What if I don't have a mobile phone?

You wouldn't use your own phone. We would give you one of our mobile phones to borrow for the research so that you can reply to the messages. The phone will have a camera too so that you can take pictures of things that are special in your life (we would ask for the phone back after the research has finished).

What if I don't know how to work a mobile phone?

We would spend some time practising how to use a mobile phone so that you felt sure how to use the phone. It's OK for somebody to help you do this too.

What should I do if I want to take part?

- If you would like to take part, then please fill in the **'Tell me more'** form, which is included in this pack. This just means that you say it is OK for me get in touch with you and that you would like to find out more.
- Then, put the **'Tell me more'** form in the envelope that is in this information pack (it already has the right address on it). Then post the envelope.
- When I see your form, I will phone or e-mail you to arrange a time and place to meet that is best for you. This will usually be in your home, but if you wanted to meet at a clinic, this could be arranged too.



Do I have to take part?

- If you do not want to meet and talk with me, just say no.
- If you say yes, but then you change your mind, that is OK too.

- This will not affect the way you are treated now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to someone you know about it.



What if I have questions about the study?



If you have any questions you can e-mail or ask someone to e-mail me - my e-mail address is psp2cd@bangor.ac.uk

Complaints

If you have any complaints about this research, please contact:

Hefin Francis (School Manager)

The School of Psychology, Bangor University,

Pen yr Allt Road,

Bangor,

Gwynedd,

LL57 2AS.

Phone number: 01248 388339

Appendix G – Opt-In Form

“Tell me more”

**I would like to take part in the research.
Please get in touch to let me know more.**

Name:



Email address:



Telephone Number:



Signed:



Date:



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Participant Information Sheet II

Thank you for posting the 'Tell me more' form and saying that you would like to find out more about the research.

Here's a reminder of what the research is about:

Natalie is going to see if taking photographs of things that are special to you helps you to feel better by sending you text messages to see:

- How you feel
- How worried you are
- How scared you are
- How happy you are with your life



What will I have to do?

1. First of all, Natalie would meet with you (either at home or at the learning disabilities team base) to ask you to answer some questions about how you feel and how worried you are. Natalie would give you a mobile phone to borrow and help to make sure you know how to send messages and take pictures. We would practice asking people if it was OK to take a picture of people. This would probably take about an hour at the meeting.



2. Then, Natalie would send you 4 text messages every 3 days (so you would only have to reply on one day and then have 2 days without sending a text).



3. After about two weeks (maybe a little bit more because we would want to make sure that you were feeling OK), Natalie would ask you start taking pictures of things that are special to you in your life.



4. When you have started taking pictures, a person from the learning disabilities team would meet with you for up to 1 hour each week (at your home or at the learning disabilities team base) to talk to you about the pictures you have taken (Natalie would still send you text messages every 3 days to see how you were feeling).



5. After you had met with one of the team 6 times to talk about the pictures you have taken, Natalie would ask you to reply to the same text messages for 2 more weeks.



6. About 2 weeks after the last text message you sent, Natalie would meet up with you again and ask you some questions about how you feel and how worried you were. Natalie would also ask you some questions about what happened in your life while you were taking part in the study. Natalie would give you £10 in this meeting as a thank you for taking part.



Will I find out what the research told us?

Yes. After the research has finished, Natalie will send you a letter in the post to tell you what we found out about taking photographs of special things in life and if it helped people to feel better.



What will happen to the messages that I send?

The answers to the messages you send will be stored on a computer programme as numbers. Nobody will know it was you that sent them and only people from the research team will be able to see them.



What happens to the photographs I take?

The photographs will be saved on the mobile phone. If you want to, you can print the pictures off and give them to the person from the team that you are seeing, but this is **only if you want to**. If you wanted to take a picture of people you know, you would need to check that this was OK with them first (and only take the picture if they say 'Yes').



If you gave any pictures to Natalie or the research team, they would be locked away in a safe place where only the research team could see them.

If we wanted to use any of the pictures to show other people, we would check that it was OK with you before.

What will happen to my information?

The information that you give will be written in a report at the end. Your real name will NOT be used in any of the reports, so no-one except Natalie and the research team would know who you were.

Whatever you say will not be shared with anybody outside our research team. But, if you tell us something that makes us worried about you or other people (such as abuse), then the research team may need to talk about this with other people, such as the police or social services, to make sure that you are safe.

If we wanted to include something you said in our written report, we would ask you first. If you said that this was OK, we would not tell anybody that it was you that said it.

What happens if I get upset because of taking photographs or sending messages about how I feel or if it makes me feel worse?

If you became upset because of taking photographs or thinking more about how you feel, you would be able to get in touch with somebody you know from the learning disabilities team to help you with your problems. It's OK to stop sending messages or taking photographs if it made you upset. If you said yes to being in the research, Natalie would write to your GP to let them know.

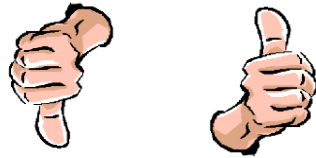


Do I still have to take part?

- If you do not want to take part, just say no.
- If you say yes, but then change your mind, that is OK too.
- This will not affect the way that you are treated now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to someone you know about it.



What if I have questions about the study?



If you have any questions you can email or ask someone to email Natalie - her email address is **psp2cd@bangor.ac.uk**

Complaints

If you have any complaints about this research, please contact:

Hefin Francis (School Manager)
The School of Psychology, Bangor University,
Pen yr Allt Road,
Bangor,
Gwynedd,
LL57 2AS.
Phone number: 01248 388399

Appendix I - Guidelines for the Functional Assessment of Capacity

Appendix: Guidelines for the Functional Assessment of Capacity

Diagnostic Threshold

The Mental Capacity Act (2005) acknowledges that if there is an established diagnosis of mental illness, intellectual disability or some other condition, then this is sufficient to confirm “impairment or disturbance of the mind”.

Nature of decision

Assessors should record the key decisions facing clients/patients

Test

1. Understanding the information

The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process

2. Retaining the information

Information only needs to be held in the mind of the person long enough to make the decision.

3. Use or weigh the information

Some people can understand the information, but an impairment stops them from using it. Whereas others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could foresee the consequences of making, or failing to make, that decision.

4. Communicate the decision

Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc).

Protocol for Assessing Capacity (Screening)

Read Information sheet once to/along with the potential participant, then say:

“To take part in this research I need to be sure you understand what I am asking you to do. If it is ok, I will just ask you some questions about what we have just read.”

Questions

1. Read the following part of the Information sheet: *“We are doing research about how you feel and how happy you are with your life. We would like to find out more by asking you to take some photographs of the important things in your life and talking to you about them.”*

Ask the participant: ***“Why do we want to meet you and ask you some questions?”***

Score 2 for a clear and accurate answer such as *“To find out about my life”* or *“To see how I feel”*.

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 if the answer is irrelevant or too vague (e.g. *“See me”*).

2. Read the following part of the Information sheet: *“Natalie will meet you help you learn how to take the photographs and reply to the text messages.”*

Ask the participant: ***“What will happen?”***

Score 2 for answer similar to *“You will come and see me teach me what to do.”*

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 for incorrect answer or an answer that is too vague.

3. Ask the participant ***“Are you happy for me to interview you?”***

Answers **Yes** or **No**.

For consent to be given the participant needs to answer Yes to question 4

4. Read the following part of the Information sheet: *“If you do not want to take part, just say no. If you say yes, but then you change your mind, that is OK too.”*

Ask the participant: ***“What will you do if you change your mind?”***

Score 2 for a clear and accurate answer such as *“tell you I don’t want to do it anymore”*

Score 1 if the person gives an answer similar to but less clear than above response

Score 0 if answer is irrelevant or too vague.

Overall scoring

		2	1	0
Question 1	Why do we want to meet you and ask you some questions?"			
Question 2	What will happen?			
Question 3	Are you happy for me to interview you?			
Question 4	What will you do if you change your mind?			

If the participant scores 0 to any of the questions under items 1, 2 or 4, then the participant is assessed as not having the capacity to consent in this specific context.

If the participant scores 2 in every question under items 1,2, and 4 and answers “Yes” to question 3, then the participant is assessed as having the capacity to consent and s/he is indicating their wish to participate. If the participant scores 2 in every question under items 1,2 and 4 but answers “No” in question 4, the participant is assessed as having the capacity to consent and is indicating their refusal to participate.

If an individual scores 1 on **all** questions it would indicate that their responses are not very clear indicating that perhaps they are not adequately understanding the information. In this situation, you will need to discuss the individual’s potential involvement with their carer or a member of staff who knows them well. Use your judgment to decide whether the individual has provided a sufficiently coherent understanding of the questions in the context of their level of intellectual disability, memory ability, and potential for suggestibility and acquiescence.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.

Appendix J – Consent Form



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Consent form

If you would like to take part in the research, you need to do two things:

Please initial boxes

QUESTIONS:

1. I have been given information about the study (Participant information sheet 1 and 2) ☐
2. I have been able to ask questions if I wanted ☐
3. I know that I can say no at any time ☐
4. I agree that my text message replies can be written in reports ☐
5. I agree to take part in this study ☐
6. I understand that I will need to give the mobile phone back to the research team at the end of the study ☐
7. I understand that the mobile phone is to be used only for the research and that any internet functions will be turned off. ☐
8. I agree to leave any internet functions turned off while I look after the phone. ☐
9. I know that I need to ask people if it is OK before I take a photo of them and not to take a photo if they don't want me to. I can do this by saying:
"Is it OK if I take a photo of you?" ☐
10. It's ok for the research team to write to my GP to let them know that I am taking part. ☐
11. I understand that if I told my therapist something that made them worry about me or somebody else, they would need to tell somebody. ☐
12. It's OK for my therapist to break confidentiality if I told them something that made them worried about me or somebody else. ☐

Participant:

Researcher:

Name.....

Name.....

Signed.....Date.....

Signed.....Date.....

Appendix K – GP Letter Template



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Miss Natalie Boulton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
43 College Road
Bangor
Gwynedd
LL57 2DG

Dr Jonathan Williams
Senior Clinical Psychologist
Denbighshire County Council
County Hall
Wynnstay Road
Ruthin
Denbighshire
LL15 1YN

Dr <Insert Name>
GP Surgery Name
Address

Dear Dr <Insert GP Name>

I am writing to inform you of <insert participant's name>'s involvement in our research project: *"Life through a lens: A pilot study investigating auto-photography and anxiety amongst people with learning disabilities"*. <Insert name>'s capacity to provide informed consent was assessed on <date> and their full informed consent was obtained on <insert date>.

The research will investigate the use of auto-photography, in which <participant name> will take photographs of things that are important in their life and respond to a series of four text messages sent to and from a mobile phone provided by the research team in relation to mood, anxiety, experiential avoidance and life satisfaction. During this time, <insert name> will attend one to one sessions with an experienced clinician from the Community Adult Learning Disabilities Team who will explore the content of the photographs.

The duration of the study is anticipated to be no longer than 10 weeks from the date of commencement <insert date>. It is not anticipated that <insert name>'s participation in the study will cause any undue distress. However, we wanted to make you aware of <insert name>'s participation, should this become apparent during the course of the study.

Please do not hesitate to get in touch if you have any questions.

Yours Sincerely,

Natalie Boulton (Trainee Clinical Psychologist)
Dr Jonathan Williams (Senior Clinical Psychologist)
Professor Robert Jones (Programme Director, North Wales Clinical Psychology Programme & Consultant Clinical Psychologist).

Appendix L - Glasgow Anxiety Scale for People with Intellectual Disabilities

Appendix I

Glasgow Anxiety Scale for People with Intellectual Disabilities

Each item scored as: (0) 'never'; (1) 'sometimes'; and (2) 'always'.

Question	Score
<i>Worries</i>	
1 Do you worry a lot? (...feel worked up/wound up/uptight/up to high doh)	
2 Do you have lots of thoughts that go round in your head? (...thoughts that you can't stop/come from nowhere)	
3 Do you worry about your parents/family?	
4 Do you worry about what will happen in the future? (tailored to the individual; e.g. What will happen if you can't live with your mum anymore?)	
5 Do you worry that something awful might happen?	
6 Do you worry if you do not feel well? (...if you feel sick)	
7 Do you worry when you are doing something new? (...like for the first time)	
8 Do you worry about what you are doing tomorrow?	
9 Can you stop worrying? (reverse score)	
10 Do you worry about death/dying?	
<i>Specific fears</i>	
11 Do you get scared in the dark? (...think of being in bed with the lights out: Would you be scared?)	
12 Do you feel scared if you are high up? (...think of being up a high building...)	
13 Do you feel scared in lifts or escalators? (Would you go in?)	
14 Are you scared of dogs? (Would you stroke/clap?)	
15 Are you scared of spiders? (Would you go near?)	
16 Do you feel scared going to see the doctor or dentist?	
17 Do you feel scared meeting new people?	
18 Do you feel scared in busy places? (...like crowds, shopping centre)	
19 Do you feel scared in wide open spaces? (...nothing round about you)	
<i>Physiological symptoms</i>	
20 Do you ever feel very hot or sweaty? (...all hot and bothered)	
21 Does your heart beat faster?	
22 Do your hands and legs shake?	
23 Does your stomach ever feel funny, like butterflies?	
24 Do you ever feel breathless? (...hard to breathe/out of breath)	
25 Do you feel like you need to go to the toilet more than usual? (...for a 'pee')	
26 Is it difficult to sit still? (...feel you can't sit at peace)	
27 Do you feel panicky? (...get into a panic/a 'state')	

Appendix M - Glasgow Depression Scale for people with a Learning Disability

Carer supplement to the Glasgow Depression Scale for people with a Learning Disability

APPENDIX 2

Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability (GDS-CS)

What is the name of the person you look after? _____
[referred to as 'X' in the following questions]

What is your relationship to X? _____

The following questions ask about how you think X has been in the last week. There is no right or wrong answer. Please circle the answer you feel best describes X in the last week.

In the last week . . .	Never/ no	Sometimes/ a little	Always/ a lot
1 Has X appeared depressed?	0	1	2
2 Has X been more physically or verbally aggressive than usual?	0	1	2
3 Has X avoided company or social contact?	0	1	2
4 Has X looked after his/her appearance?	2	1	0
5 Has X spoken or communicated as much as he/she used to?	2	1	0
6 Has X cried?	0	1	2
7 Has X complained of headaches or other aches and pains?	0	1	2
8 Has X still taken part in activities which used to interest him/her?	2	1	0
9 Has X appeared restless or fidgety?	0	1	2
10 Has X appeared lethargic or sluggish?	0	1	2
11 Has X eaten too little/too much?	0	1	2
If no problem, score 0. (A positive answer to either question means it should be scored. Please tick which response is relevant, beside the question.)			
12 Has X found it hard to get a good night's sleep? Please also tick which one of the following options is relevant. Has X had difficulty falling asleep when going to bed at night? <input type="checkbox"/> Has X been waking in the middle of the night and finding it hard to get back to sleep again? <input type="checkbox"/> Has X been waking very early in the morning and finding it hard to get back to sleep? <input type="checkbox"/>	0	1	2
13 Has X been sleeping during the day?	0	1	2
14 Has X said that he/she does not want to go on living?	0	1	2
15 Has X asked you for reassurance?	0	1	2
16 Have you noticed any change in X recently? Please explain what changes you have noticed, in either mood or behaviour. _____ _____ _____	0	1	2

Thank you for answering these questions.

Appendix N - Bangor Life Events Schedule for Intellectual Disabilities V1.1

Bangor Life Events Schedule for Intellectual Disabilities: Self-Report Semi-Structured Interview V1.

Bangor Life Events Schedule for Intellectual Disabilities Scoring Approaches

Bangor Life Events Schedule for Intellectual Disabilities

V1.1

Instructions for Completion of the BLESID

The BLESID is designed as a measure of significant life events occurring in the life of someone with an intellectual disability within the last twelve months. This version should be completed by a family member or carer who knows the individual well.

The schedule consists of 38 questions, grouped into topics. If an event hasn't been experienced by the person with intellectual disabilities **in the last twelve months**, place a circle around 'Did not happen'.

If the event did happen, circle the option to indicate how many times it happened, when it happened, and then circle to indicate how much the event impacted on the person's life.

"Considerable positive impact" means the person seemed to become much happier or more content because of the event for some time afterwards.

"Some positive impact" means the person especially enjoyed the event or experienced a happier mood for a short while following the event.

"No impact" means that you weren't aware of the event having any effect on the person.

"Some negative impact" means the person especially disliked or was upset by the event or experienced a more sad, angry or anxious mood for a short while following the event.

"Considerable negative impact" means the person seemed to become much more sad, angry or anxious because of the event for some time afterwards.

Example

"Jane had a severe chest infection that required three weeks in hospital. Throughout she was very unhappy and often wept. Even now, after seven months of good health she sometimes mentions the hospital and says she never wants to go there again." Here's how item 1.1 would be completed...

		Frequency			Time			Impact				
		Did not happen	Happened once	More than once	Last 3 months	Last 6 months	Last 12 months	Considerable negative impact	Some negative impact	No impact	Some positive impact	Considerable positive impact
1	Health											
1.1	Illness or injury requiring hospitalisation	0	1	2	3	6	12	--	-	0	+	++

		Frequency			Time			Impact				
		Did not happen	Happened once	More than once	Last 3 months	Last 6 months	Last 12 months	Considerable negative impact	Some negative impact	No impact	Some positive impact	Considerable positive impact
1 Health												
1.1	Illness or injury requiring hospitalisation	0	1	2	3	6	12	--	-	0	+	++
1.2	Serious illness or injury <i>not</i> requiring hospitalisation	0	1	2	3	6	12	--	-	0	+	++
1.3	'Near miss' or 'lucky escape' from an accident	0	1	2	3	6	12	--	-	0	+	++
1.4	Menopause	0	1		3	6	12	--	-	0	+	++
1.5	Being sectioned under the Mental Health Act	0	1	2	3	6	12	--	-	0	+	++
1.6	Introduction, withdrawal or change in medication	0	1	2	3	6	12	--	-	0	+	++
1.7	Becoming pregnant	0	1	2	3	6	12	--	-	0	+	++

1.8	Problems with alcohol or other drugs	0	1	2	3	6	12	--	-	0	+	++
2 Support and Living Arrangements												
2.1	Moved room, or change in decoration/furniture	0	1	2	3	6	12	--	-	0	+	++
2.2	Moved house	0	1	2	3	6	12	--	-	0	+	++
2.3	Moved out of long stay hospital	0	1	2	3	6	12	--	-	0	+	++
2.4	Other person moved into or out of house/flat/unit	0	1	2	3	6	12	--	-	0	+	++

		Frequency			Time			Impact				
		Did not happen	Happened once	More than once	Last 3 months	Last 6 months	Last 12 months	Considerable negative impact	Some negative impact	No impact	Some positive impact	Considerable positive impact
2.5	Period of cover by non-regular carer (e.g. agency or other family member)	0	1	2	3	6	12	--	-	0	+	++
2.6	Permanent change in staffing	0	1	2	3	6	12	--	-	0	+	++
2.7	Being physically restrained	0	1	2	3	6	12	--	-	0	+	++
2.8	Change in daily routine	0	1	2	3	6	12	--	-	0	+	++
2.9	Holiday or substantial trip	0	1	2	3	6	12	--	-	0	+	++
2.10	Being taken to an unusual place (e.g. large meeting or case review)	0	1	2	3	6	12	--	-	0	+	++
3 Crime												
3.1	Victim of theft	0	1	2	3	6	12	--	-	0	+	++

3.2	Victim of violence	0	1	2	3	6	12	--	-	0	+	++
3.3	Victim of sexual abuse	0	1	2	3	6	12	--	-	0	+	++
3.4	Subjected to verbal abuse	0	1	2	3	6	12	--	-	0	+	++
3.5	Witnessed physical attack or verbal abuse on another	0	1	2	3	6	12	--	-	0	+	++
3.6	Arrested by police or formally questioned about committing a crime	0	1	2	3	6	12	--	-	0	+	++

		Frequency			Time			Impact				
		Did not happen	Happened once	More than once	Last 3 months	Last 6 months	Last 12 months	Considerable negative impact	Some negative impact	No impact	Some positive impact	Considerable positive impact
4 Occupation & Financial Occupation includes school, college, work, and day services.												
4.1	Started occupation or returned to occupation after long absence				3	6	12					
		0	1	2				--	-	0	+	++
4.2	Change of place of occupation	0	1	2	3	6	12	--	-	0	+	++
4.3	Retired or stopped attending place of occupation	0	1	2	3	6	12	--	-	0	+	++
4.4	Increase in allowance or spending money	0	1	2	3	6	12	--	-	0	+	++
4.5	Decrease in allowance or spending money	0	1	2	3	6	12	--	-	0	+	++
4.6	Financial problems	0	1	2	3	6	12	--	-	0	+	++

5 Relationships												
5.1	Death of close friend or relative	0	1	2	3	6	12	--	-	0	+	++
5.2	Death of a nonfamily carer	0	1	2	3	6	12	--	-	0	+	++
5.3	Serious illness of close relative	0	1	2	3	6	12	--	-	0	+	++
5.4	Separation from friend/family/longtime carer	0	1	2	3	6	12	--	-	0	+	++
5.5	Break up of steady relationship or marriage	0	1	2	3	6	12	--	-	0	+	++
		Frequency			Time			Impact				
		Did not happen	Happened once	More than once	Last 3 months	Last 6 months	Last 12 months	Considerable negative impact	Some negative impact	No impact	Some positive impact	Considerable positive impact
5.6	Break up of friendship	0	1	2	3	6	12	--	-	0	+	++
5.7	Increased arguments with others	0	1	2	3	6	12	--	-	0	+	++
5.8	Increase or decrease in visits to/from other family members	0	1	2	3	6	12	--	-	0	+	++

Other

If any important events have happened in the person's life that are not covered above, please use the space below to tell us about them.

Anniversaries

People are sometimes affected by events in their lives long after the event is over. These sorts of effects are particularly noticeable when there are special reasons to remember the event, such as the anniversary of its occurrence. Are you aware that the person has been affected by an event in this way? Please give details.

Bangor Life Events Schedule for Intellectual Disabilities

Self Report Semi-Structured Interview

V1

Instructions for Completion of the BLESID-SR

The BLESID is designed as a measure of significant life events occurring in the life of someone with an intellectual disability within the last twelve months. This version should be completed by a professional with experience conducting semi-structured interviews.

The schedule consists of 24 life events, grouped into topics. The schedule is not intended for item-by-item questioning of the interviewee. Rather, it should be used to guide a semi-structured interview. Interviewees should be given time to express themselves in their own words and the interviewer should ask follow-up questions *ad libitum* to clarify what the interviewee has experienced.

Before the interview begins the interviewer should, if at all possible, establish an event that occurred approximately twelve months prior to the interview as an anchor point. This procedure has been shown to aid the participant in deciding which events have occurred in the previous twelve months. Questions can be asked for clarification: "Did this happen since your room was repainted?"

At the beginning of the interview the interviewer should take some time to establish rapport with the client. The types of events asked about in this schedule are personal in nature and unnecessary disquiet may be caused if insufficient rapport exists between the interviewer and interviewee.

Visual prompts are provided at the end of this booklet and may be used as necessary as a clarifier for the impact dimension. Interviewees will often express whether an event was positive or negative in their description of the event and a separate question thus becomes unnecessary.

Optional information on **when the event occurred** can be recorded in the last column of this record form.

The nature of the schedule is such that questions can be made to flow into one another in a manner approximating normal conversation. For example, here's how the first two items might be covered.

Q: Have you been ill at all since [anchor event]?
A: Uh... no.
Q: That's good. You've not been in hospital or anything?
A: No. Not been to hospital.
Q: Do you take any medicines or pills?
A: Only when I'm ill or something.
Q: Like if you have a cold?
A: Yeah. I don't take 'em normally.

By asking a general question about whether any medication is taken the interviewer might avoid the potentially more complex question about a *change* in medication. Such an approach can be used throughout and familiarity with the schedule is therefore imperative.

		Don't know	Frequency			Impact			When?
			Did not happen	Happened once	More than once	'Bad'	'In the middle'	'Good'	
1 Health									
1.1	Illness or injury requiring hospitalisation	DK	0	1	2	-	0	+	
1.2	Serious illness or injury <i>not</i> requiring hospitalisation	DK	0	1	2	-	0	+	
1.3	Introduction, withdrawal or change in medication	DK	0	1	2	-	0	+	
2 Support and Living Arrangements									
2.1	Moved room, or change in decoration/furniture	DK	0	1	2	-	0	+	
2.2	Moved house	DK	0	1	2	-	0	+	
2.3	Other person moved into or out of house/flat/unit	DK	0	1	2	-	0	+	
2.4	Period of cover by nonregular carer (e.g. agency or other family member)	DK	0	1	2	-	0	+	

2.5	Permanent change in staffing	DK	0	1	2	- 0 +	
2.6	Holiday or substantial trip	DK	0	1	2	- 0 +	
2.7	Being taken to an unusual place (e.g. large meeting or case review)	DK	0	1	2	- 0 +	
3 Crime							
3.1	Victim of theft	DK	0	1	2	- 0 +	
3.2	Subjected to verbal abuse	DK	0	1	2	- 0 +	
3.3	Arrested by police or formally questioned about committing a crime	DK	0	1	2	- 0 +	
4 Occupation & Financial Occupation includes school, college, work, and day services.							
4.1	Started occupation or returned to occupation after long absence	DK	0	1	2	- 0 +	
4.2	Change of place of occupation	DK	0	1	2	- 0 +	
4.3	Retired or stopped attending place of occupation	DK	0	1	2	- 0 +	
4.4	Increase in allowance or spending money	DK	0	1	2	- 0 +	
4.5	Decrease in allowance or spending money	DK	0	1	2	- 0 +	
5 Relationships							
5.1	Death of close friend or relative	DK	0	1	2	- 0 +	
5.2	Death of a non-family carer	DK	0	1	2	- 0 +	
5.3	Serious illness of close relative	DK	0	1	2	- 0 +	
5.4	Break up of steady relationship or marriage	DK	0	1	2	- 0 +	
5.5	Break up of friendship	DK	0	1	2	- 0 +	
5.6	Increase or decrease in visits to/from other family members	DK	0	1	2	- 0 +	

Other	
-------	--

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins or other markings visible.

Anniversaries

237

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Good



In the middle



Bad

BLESID Scoring Approaches

N.B. Whilst the separate sections of the BLESID do reflect different domains of life, life events are largely independent from one another and so the sections are not subscales, as usually defined in psychometrics. Unless one is interested in studying a particular class of life events therefore, totals will most fruitfully be computed with regards to the whole BLESID scale.

Frequency Total

The most straightforward way to compute a total from the BLESID is in lines with early Holmesian scales and other scales currently in use with people with intellectual disabilities such as the first section of the PAS-ADD. The basic assumption is that 'a life event' is an appropriate unit of measurement. If we make this assumption then a meaningful total can be arrived at by computing a sum of frequency scores for each participant, with 'more than once' taking a value of two, and thus contributing more to the total than a single occurrence of a life event.

Impact Total

According to the resource loss theory propounded by Stevan Hobfoll, one may view life events as discrete occurrences that confer either a gain or loss in resources. (Resources here are thought of in the most generic way and might include friendships, money, etc.) If one thinks about life events in this way then it makes sense to take account of good life events when computing any sort of total. From the BLESID, the best way we might do this is to simply sum impact scores.

Product Total

The frequency total method takes account of the number of events but neglects their valence (good and bad events are counted similarly). The impact total method plays good and bad events off against each other but pays no heed to whether an event occurred multiply. A product total takes both aspects of a life event into account by first multiplying the frequency score and impact score of a life event, then adding all these products up for a participant.

Negative Only Totals

Whilst this approach does not fit well with Hobfoll's resource theory, there is some empirical evidence (Esbensen & Benson, 2006) that only events that are rated as negative in the particular context of a participant's life have an effect on challenging behaviour or mental health. This might lead us to suggest computing either the impact or product total methods above whilst only including those events which are rated as negative in impact.

Esbensen, A. J., & Benson, B. A. (2006). A prospective analysis of life events, problem behaviours and depression in adults with intellectual disability. *Journal of Intellectual Disability Research*, 50(4), 248-258.

Appendix O – FireText Privacy and Lost Data Policy

Email correspondence with FireText Marketing Manager (26th February 2015):

Security is our number one priority here and data is not shared between accounts or with any other third parties, mobile numbers are strictly used by you, FireText don't have access to these and will not share them or pass them on, I've copied a link to our Privacy Policy which might help: <http://www.firetext.co.uk/privacy/> if you have any questions on this - let me know!

In terms of lost data, we have a very strict back-up policy which takes place every hour and every day.

We've also recently been approved by the government's digital marketplace: G Cloud.

Kind regards
Holly

FireText Support
e: holly@firetext.co.uk
w: www.firetext.co.uk
t: 0800 038 5522

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


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Appendix P – Exemplar Fire Text Message Replies

Appendix P: Text Messages sent to participants via FireText online SMS system every 3 days

sms made easy

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[Keywords](#)

1336 Credits Remaining
[TOP UP NOW](#)

Messages Sent

Sent Received

View by Group: All Contacts Display: 10 25 50 100

Date	Time	Recipients	Message	
22/10/15	16:14	4 - All Contacts	How HAPPY are you today? 1(not happy atall) :(2(not very happy) 3(in the middle) 4(a fair bit happy...(more)	VIEW >
22/10/15	16:13	4 - All Contacts	How HAPPY are you today? 1(not happy atall) :(2(not very happy) 3(in the middle) 4(a fair bit happy...(more)	VIEW >
22/10/15	16:03	4 - All Contacts	How SCARED are you to do the things you want to do? 1(not scared at all) 2(not very scared) 3(in the... (more)	VIEW >
22/10/15	16:01	4 - All Contacts	How WORRIED are you today? 1(no worries) 2(not very worried) 3(in the middle) 4(a fair bit worried)... (more)	VIEW >
22/10/15	15:59	4 - All Contacts	Hi! You are about to receive a few messages. Please text back the number most true for you today...	VIEW >
19/10/15	16:50	1 - individual	Thanks for taking the time to read the messages. Thanks for your replies :)	VIEW >
19/10/15	16:45	1 - individual	Today I like my life" 1(my life is rubbish) 2(I don't like my life very much) 3(in the middle) 4(I ... (more)	VIEW >
19/10/15	16:43	1 - individual	"Today I feel HAPPY" 1(not happy atall) :(2(not very happy) 3(in the middle) 4(a fair bit happy) 5(... (more)	VIEW >
19/10/15	16:43	1 - individual	"Today I feel scared to do the things I want to do" 1(not scared at all) 2(not very scared) 3(in the... (more)	VIEW >
19/10/15	16:42	1 - individual	"Today I feel WORRIED" 1(no worries) 2(not very worried) 3(in the middle) 4(a fair bit worried) 5(ve... (more)	VIEW >
19/10/15	16:40	1 - individual	Hi! You are about to receive a few messages. Please text back the number most true for you today...	VIEW >
19/10/15	14:21	1 - individual	Thanks for taking the timeto read the messages. Thanks for your replies :)	VIEW >
19/10/15	14:19	1 - individual	Today I like my life" 1(my life is rubbish) 2(I don't like my life very much) 3(in the middle) 4(I ... (more)	VIEW >
19/10/15	14:18	1 - individual	"Today I feel HAPPY" 1(not happy atall) :(2(not very happy) 3(in the middle) 4(a fair bit happy) 5(... (more)	VIEW >
19/10/15	14:17	1 - individual	"Today I feel scared to do the things I want to do" 1(not scared at all) 2(not very scared) 3(in the... (more)	VIEW >
19/10/15	14:16	1 - individual	"Today I feel WORRIED" 1(no worries) 2(not very worried) 3(in the middle) 4(a fair bit worried) 5(ve... (more)	VIEW >
19/10/15	14:15	1 - individual	Hi! You are about to recieve a few messages. Please text back the number most true for you today...	VIEW >
19/10/15	10:40	1 - individual	Thanks for taking the timeto read the messages. Thanks for your replies :)	VIEW >
19/10/15	10:38	1 - individual	"Today I like my life" 1(my life is rubbish) 2(I don't like my life very much) 3(in the middle) 4(I ... (more)	VIEW >
19/10/15	10:38	1 - individual	"Today I feel HAPPY" 1(not happy atall) :(2(not very happy) 3(in the middle) 4(a fair bit happy) 5(... (more)	VIEW >
19/10/15	10:37	1 - individual	"Today I feel scared to do the things I want to do" 1(not scared at all) 2(not very scared) 3(in the... (more)	VIEW >

Appendix Q – Mobile Phone Overview and Specification

Nokia 108: Phone Specification



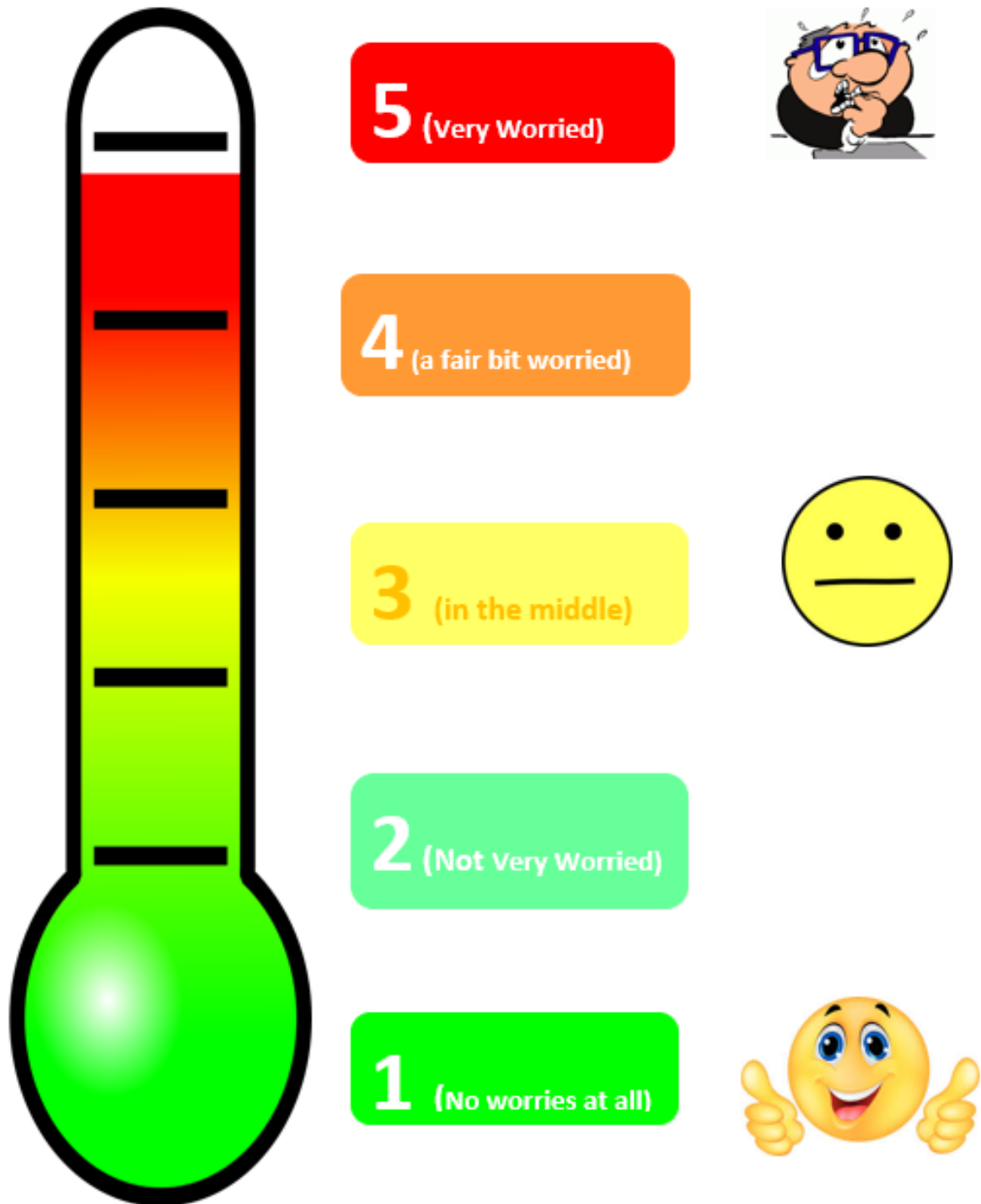
Also known as Nokia 108 with single-SIM card slot

NETWORK	Technology	GSM
	2G bands	GSM 900 / 1800 - SIM 1 & SIM 2
	GPRS	No
	EDGE	No
LAUNCH	Announced	2013, September
	Status	Available. Released 2013, October
BODY	Dimensions	110.4 x 47 x 13.5 mm, 70.1 cc (4.35 x 1.85 x 0.53 in)
	Weight	70.2 g (2.47 oz)
	SIM	Dual SIM (Mini-SIM, dual stand-by)
		- Flashlight
DISPLAY	Type	TFT, 65K colors
	Size	1.8 inches (~19.7% screen-to-body ratio)
	Resolution	128 x 160 pixels (~114 ppi pixel density)
MEMORY	Card slot	microSD , up to 32 GB (dedicated slot)
	Phonebook	500 contacts
	Call records	Yes
	Internal	4 MB RAM
CAMERA	Primary	VGA
	Video	320p@15fps
	Secondary	No
SOUND	Alert types	Vibration, Polyphonic(32), MP3 ringtones
	Loudspeaker	Yes
	3.5mm jack	Yes

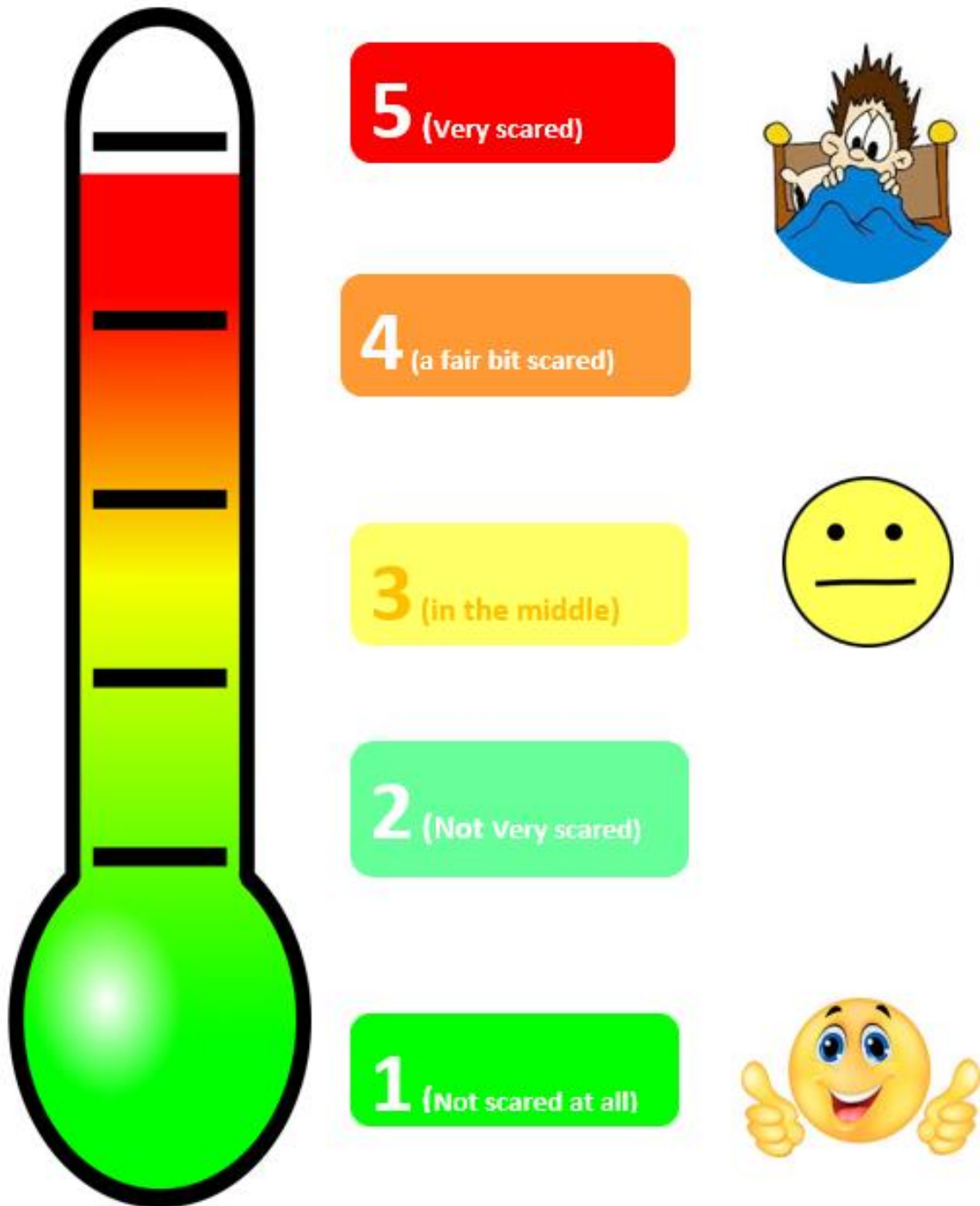
COMMS	WLAN	No
	Bluetooth	v3.0
	GPS	No
	Radio	Stereo FM radio, RDS
	USB	No
FEATURES	Messaging	SMS(threaded view)
	Browser	No
	Games	Yes
	Java	Yes
		<ul style="list-style-type: none"> - WAV/MP3/AAC player - MP4/H.263 player - Digital clock - Calculator - Calendar - Converter
BATTERY		Removable Li-Ion 950 mAh battery (BL-4C)
	Stand-by	Up to 600 h
	Talk time	Up to 13 h 40 min
	Music play	Up to 41 h
MISC	Colors	Black, White, Red, Blue, Yellow
	SAR EU	1.30 W/kg (head) 0.80 W/kg (body)
	Price group	<u>1/10</u>

Appendix R - 'Easy Read' Thermometers to facilitate self-report anxiety, mood, experiential avoidance and life satisfaction scores
(A4, Wallet-Sized and Key-Ring Versions).

How WORRIED are you today?



How SCARED are you to do the things you want to do?



How HAPPY are you today?



5 (Very Happy)



4 (a fair bit happy)



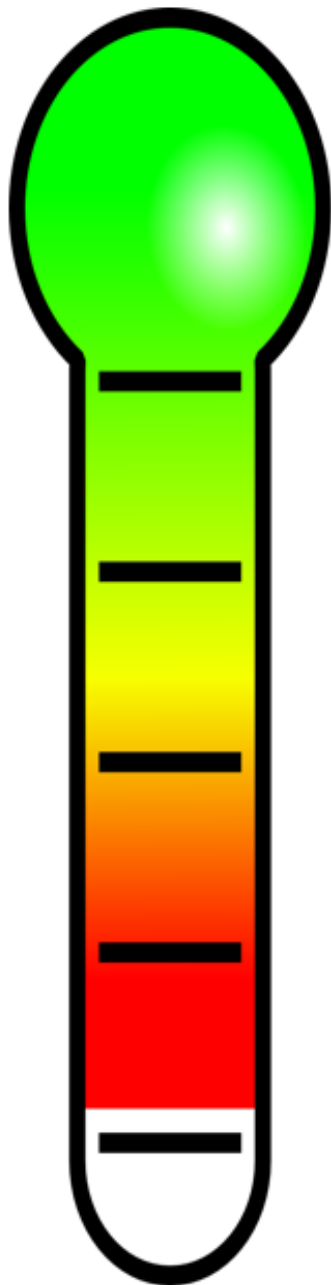
3 (in the middle)

2 (Not Very happy)

1 (Not happy at all)



Do you LIKE your LIFE today?



5 (I love my life)



4 (I like my life a fair bit)



3 (in the middle)

2 (I don't like my life very much)

1 (My life is rubbish)



Easy-Read Text Message Scoring: Wallet & Key Ring Versions











Wallet/Purse size

Key-ring version:



Appendix S – Example Text Message Reminder Calendar

Month Year						Name	
Remember: Natalie will let you know when to start taking photos							
Text Message Dates				(When Natalie will text you to ask how you are doing)			
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	
					1	2	
3	4	5	6	7 Meet with Natalie to practice using phone	8	9	
10 	11	12	13 	14 	15	16	
17 	18	19	20 	21	22	23	
24 	25	26	27	28 	29	30	

Appendix T - *Catching What Matters* Treatment Manual for Therapists

Treatment Manual for Therapists

Version 1. 14.03.16



Contents

1. Catching What Matters: Using photos to cope with worries and follow your heart	
1.1 Theoretical background and practical issues.....	3
1.2 Practical issues for consideration.....	5
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Part One: Theoretical Background and practical issues

Autophotography for people with learning disabilities who experience anxiety



Adults with learning disabilities experience mental health difficulties including anxiety (Cooray & Bakala, 2005). There are a number of reasons for this, including social, psychological, developmental and biological factors.

In the past, research has used traditional talking therapies as a way of helping people with learning disabilities to manage their anxiety. Talking about life in this way can be difficult for some people with learning disabilities.

Autophotography (taking photos of valued aspects of life) lends itself to active inclusion in the therapeutic setting for people who may find it difficult to express their views and feelings.



Catching My Worries is a six-session intervention which combines a values-based approach (Acceptance and Commitment Therapy, Hayes et al., 2011) with taking photographs of important aspects of life. A key component of the Acceptance and Commitment Therapy (ACT) model is its focus on supporting individuals to reconnect with important aspects of life, supporting committed action in a valued life direction. The ultimate aim of ACT is to empower individuals to live the life they want to live, rather than avoiding aspects of life that make them feel anxious (Jackson-Brown & Hooper, 2009).

The resources included within this work book have been designed to be used by people with learning disabilities along with their therapist and, in some cases, alongside a support person. The support person could be a family member or support worker. Although all of the materials have been designed to be accessible, some individuals with learning disabilities may have few, if any, literacy skills. This means that the therapist has an

important role in helping the person with learning disabilities to make sense of the session materials and guide the person through the stages of the intervention, ensuring that the venture is collaborative.

Aim of Catching my Worries:



Our aim is to help people with learning disabilities to focus more on valued aspects of life.

What will happen to the results?



The results will inform future therapeutic work and the feasibility of the use of mobile phones, text messaging and autophotography for people with learning disabilities.

Where can I find out more?



For further information about Acceptance and Commitment Therapy and the underlying theory and principles, you may find it helpful to read Hayes et al.'s (2011) book outlining the treatment model.

References:

Cooray, S.E. & Bakala, A., (2005). Anxiety disorders in people with learning disabilities. *Advances in Psychiatric Treatment*. 11, 355-361.



Hayes, S.C., Kirk, D., Strosahl, K.G. & Wilson, K.G. (2011). Acceptance and Commitment Therapy, Second Edition: *The Process and Practice of Mindful Change*. New York: Guilford Press.

Jackson-Brown, F., Hooper, S. (2009). Acceptance and commitment therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts. *Journal of Intellectual Disabilities*, 13, 195-200. doi: 10.1177/1744629509346173

Practical Issues for consideration:

Accommodation:



Sessions will usually take place on an outreach basis, at the participant's home or day centre. The chosen location should be a place where the participant feels comfortable and a suitable space is available for the photos to be discussed privately. Should the participant choose for the therapist not to visit their home, it is advisable to meet in an alternative suitable setting, such as a clinic.

Selection of participants:



The researcher will meet with participants for a screening session before they enrol in the study. This is to ensure that the participant is suitable to take part and provide them with an



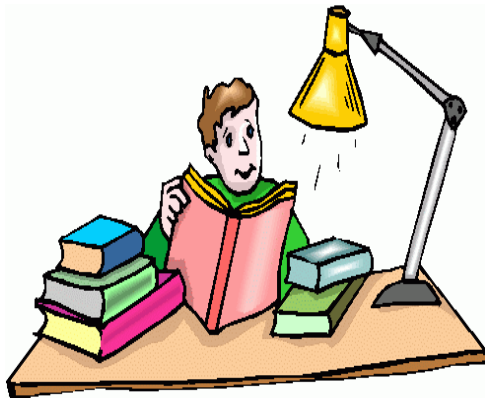
opportunity to ask any questions that they may have. The participant's capacity to provide informed consent is assessed as part of this initial screening session. Successful completion of the screening, consent and assessment of functional capacity to consent will be taken as evidence of sufficient verbal understanding and communication skills to take part in therapy. Literacy skills are not required (participants may be supported to read and reply to text messages asking them to rate their levels of anxiety, experiential avoidance, mood and life satisfaction).

Therapists:



Therapists should have excellent communication skills and be competent in the development of collaborative therapeutic relationships with participants and those supporting them. Experience of delivering psychological interventions to people with learning disabilities is essential. Potential therapists will be required to be working at a minimum of Band 6 on the NHS Agenda for Change scale for health workers in the UK, allowing them to deliver interventions that are underpinned by theory.

Preparation/Familiarising yourself with the manual:



As the therapist, your role is to facilitate the sessions. This means that a **good understanding of the manual and adequate pre-session preparation is essential**. Ideally, you should familiarise yourself with the full manual content and strategies before starting therapy. In order to make sense of the individual sessions, it is helpful to know how they fit in to the structure of the intervention as a whole. **As this intervention is being delivered as part of a research study, it is really important to adhere to the instructions in the manual and the model being described.**



If you have any queries or are still in doubt after reading the manual, remember that you can contact the researcher for further guidance.

Number of sessions and timing

The intervention is planned for six weekly sessions. Holidays, illness or unforeseen circumstances may mean that sessions are occasionally held less frequently. Where possible, strive to ensure that this does not happen on more than 3 occasions.



Individual sessions will last approximately 1 to 1.5 hours. When sessions last for more than an hour, a short break should be scheduled, perhaps for a cup of tea.

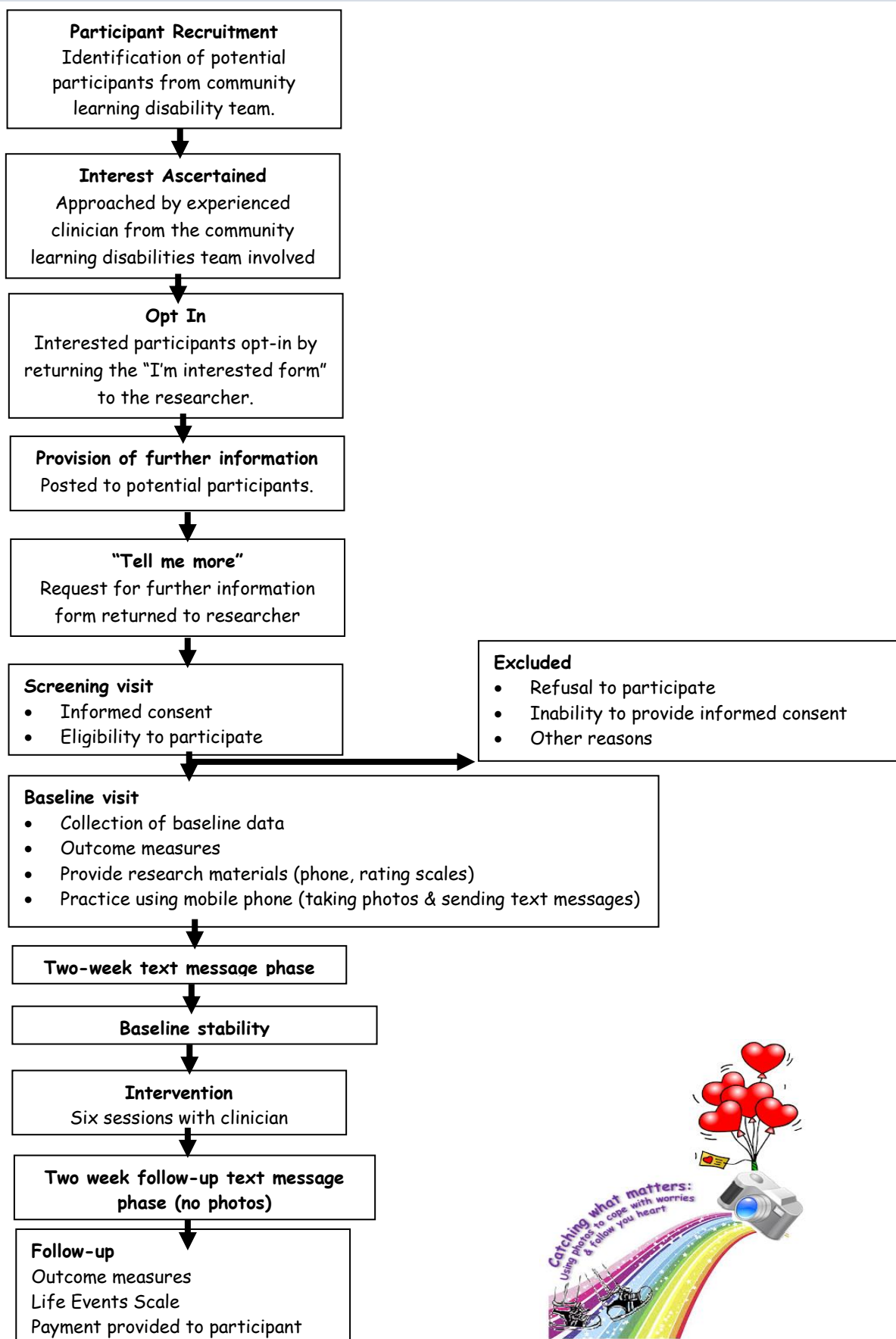
- Participants will be allocated to therapists as soon as they achieve baseline stability (3 stable data points for self-reported levels of anxiety). We are able to tell when they have reached this point by the scores of the text messages they send to the researcher. **Therapy should start as soon as possible after the participant is assigned to you.**
- The researcher will provide you with an overview of the participant, including contact details at this time.

Part Two:

Session Plans



A Participant's Research Journey



Overview of sessions

Session	Main Aims
1	To build rapport with the participant and collaboratively explore their life values.
2	To help the participant to recognise and clarify their own life values by taking photos of things that are really important in their life.
3	To clarify which values are important and explore how closely these are being lived towards at the moment.
4	Help participants to broaden their values base and to identify and problem-solve barriers to engaging in things related to domains that are important.
5	To further clarify (in fine grain detail) values and consider some committed action (doing the things that are important and taking photos as they go along).
6	To consider future planning and living towards values in the short and longer term.

2.1:

Session 1



2.1: Session 1

Introduction to autophotography and exploring your life values

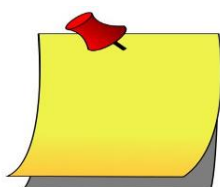
Session Overview



This is an introductory session which provides an opportunity for the participant and therapist to get to know each other. The therapist provides further information about autophotography and participants are introduced to the concept of life values. Therapeutic aims are to build rapport with the participant and collaboratively explore their values.

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Post-session frequency data collection sheet (Appendix 3)
- Appointment slip (Appendix 4)



Note for therapist:

Although this will be the first time you have met the participant, try your best to foster a relaxed atmosphere and help the participant to feel at ease. Perhaps consider having a cup of tea or coffee and a short informal chat at the start of the session, before providing an overview of the session.



Activities:



1. Introduction (10 – 15 minutes)

- **Introduce yourself as the *Catching What Matters* therapist** and provide a brief overview of your role. Do this by explaining to the participant that you will meet with them for six sessions to talk about the photos they have taken. Explain that this will happen weekly where possible, although there may be times due to holidays, sickness or unforeseen circumstances (for

participant or therapist) when sessions may take place less frequently.

- **Recap the limits of confidentiality** and let the participant know that you have a duty to follow safeguarding procedures if the participant tells you something that makes you worry about their safety or the safety of others. The researcher has discussed this previously with the participant, at the initial screening session.



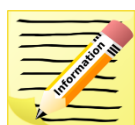
- Ask the participant if they have any questions or queries at this time, before the session begins by saying:

"Do you have any questions before we start?"

If the participant has queries at this point, spend some time making sure that you try your best to respond to their questions/queries so far as possible and endeavour to find out information for them if you are unsure. You can do this by contacting the researcher.

- ☐ Introduce self
- ☐ Remind the participant of your role
- ☐ Recap limits of confidentiality
- ☐ Answer any queries the participant may have

N.B: This list of tick boxes will be included in each session plan. You can use these to help guide the session if you feel this helps you. Consider working collaboratively with the participant in ensuring that all aspects of the work book are covered as you go along.



2. Further information about the study (5-10 minutes):

What is autophotography?

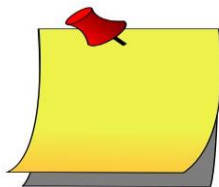
Here, the therapist outlines what autophotography is. Do this by explaining to the participant that ***"autophotography means taking photos of things that matter to you; the things that are really important in your life."***

Why autophotography?

Explain to the participant that taking photos of things that matter to you can help people with learning disabilities who have anxiety to clarify their values (valued organising patterns of behaviour) and this might help to manage anxiety and the effects of anxiety on a person's life. You could do this by saying:



"Sometimes when we feel anxious or worried, our worries can get in the way of important things in our lives...taking photos can help us to get in touch with the things that are really important in our hearts."



Note for therapist:

It may be useful for the therapist to illustrate this key point by providing some examples here, such as: if we feel worried about going to busy places, we might be scared to leave the house and get on the bus to go and see our family or friends that we really care about. Or, we might avoid doing other things like going to concerts to see our favourite bands or football matches to see our favourite team play, even though these might be really important to us.

- ☐ Explain what autophotography is
- ☐ Outline how autophotography might help
- ☐ Provide examples to illustrate explanation
(if appropriate).

3. Looking at the photos together (15-20 minutes)



Review Photos the photos taken so far.

Do this by asking the participant to show you the photos that they have taken up to now. Ask the participant to describe what they have taken a picture of and encourage wider discussion of the photo.

What if the participant has not taken any photos?

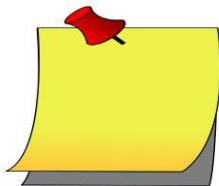
If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together - think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

For example, potential obstacles could be:

"I didn't know what to take pictures of" - if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" - consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (for example - using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.)

"I forgot to take the phone with me," - spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a reminder on a calendar, setting a reminder on their phone (or the research phone).

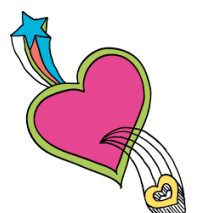


Note for therapist:

When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

4. Introducing Values (15-20 minutes)

Introduce the concept of values by working through the **values worksheet** (Appendix 1) together.



Using the **values diagram worksheet** (Appendix 2), have a look at the domains listed and further explore the participant's views on each domain. Note relevant comments on the worksheet -do this collaboratively with the participant. Perhaps ask the participant whether they would like to write or draw the things that are being talked about on the worksheet.

- ☐ Looking at the photos together.
- ☐ Introduce values
- ☐ Discuss values domains.

5. Ending the session: (5-10 minutes)

- Draw the session to a close by briefly **reviewing what you have covered** in the session.
- **Thank the participant** for their role in the session today.
- Once again check whether the participant has **any questions or queries** and answer in the best way you can.
- Ask the participant whether they have enough **phone credit** on the research mobile phone. **If they require a top-up, let the researcher know.**
- **Arrange a time and date for the next session** and write it on the appointment slip (Appendix 4) to be left with the participant (let support staff know if this is appropriate and has been agreed with the participant).

- ☐ Review today's session
- ☐ Thank participant
- ☐ Any questions?
- ☐ Arrange time, date and location of next session.
- ☐ Remind participant to continue to take photos
- ☐ Check phone credit - do they need a top-up?

6. After the session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.



Complete:

☐

Post-session frequency data sheet.

2.2

Session 2



2.2: Session 2

Session Overview



In this session, the therapist encourages the participant to take photos of things that are important to them in as many values domains as possible. The session aims are to help the participant to recognise and gain greater insight into their own life values by taking pictures of things that are really important in their life.

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Post-session frequency data collection sheet (Appendix 3)
- Appointment slip (Appendix 4)



Activities:



1. Recap the previous session (10 - 15 minutes)

Ask the participant what they can remember from the last session. Work through any questions or queries about the intervention that the participant may have that have arisen since the last session.

☐

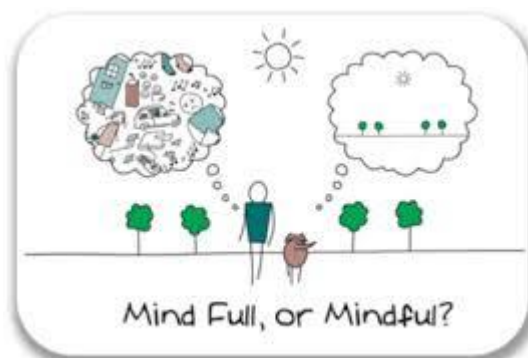
Recap last session.

2. Review the photos (30-40 minutes)

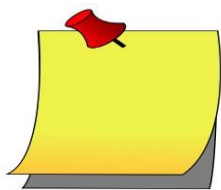


Ask the participant to show you the photos that they have taken over the previous week. Provide assistance with the mobile phone to do this if required. Look through the photos together, asking the participant to describe the photos they have taken.

- As each photo is explored, ask the participant which value domain they it relates to. Working together, make a note of the domains on the **values diagram** (Appendix 2). Be sure to ask the participant if they would like to write or draw this on the sheet or whether they would prefer that the therapist did this).



Note for therapist:

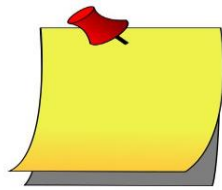


In-Vivo Mindfulness of the Photos

When you are looking at the photos with the participant, really, really slow down the pace of the session. Do this by slowing down your speech and talking very slowly. Ask the participant to slow down their speech too when they are talking about the photos. If you consider that a photo has been talked through by the participant too quickly (at a particularly fast pace), ask the participant to repeat their description of the photo, at a slower pace this time.

- As the photos are explored, really encourage the participant to tell you about all of the different elements that are in the picture.
- Ask the participant what comes up for them when they are describing the picture to you in that moment (do they notice any thoughts, feelings, physiological sensations, emotions, urges?)
 ➔ If so, explore these further with the participant and be curious about how this experience is for them. You may ask questions such as ***"how does your body feel when you have that thought?"***
Encourage the participant to really connect with the emotional experience associated with exploration of their values.

Note for therapist:



*This aspect of the intervention where the participant is asked to really slow down their speech may seem unusual to the participant at first and may take some practice. Acknowledge this with the participant by saying *"this may seem strange to do at first, we're not very used to talking like this normally."*

Then, outline the rationale behind this approach. You could say: *"sometimes, we say things really quickly without realising what we are saying or what we really mean. When we slow our voice and words down, we can really start to connect with the things we are talking about. Because our work together is to help to really find out what your values are, talking in this way can help us to do that."*

What if the client has not taken any photos?

If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together - think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

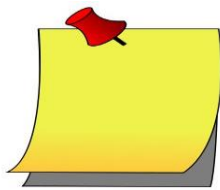
For example, potential obstacles could be:

"I didn't know what to take pictures of" - if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" - consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (for example - using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.)

"I forgot to take the phone with me," - spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a

reminder on a calendar, setting a reminder on their phone (or the research phone).



Note for therapist:

When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

- ☐ Review the photos
- ☐ Relate photos to domains
- ☐ In-vivo mindfulness of photos.
- ☐ Explain rationale for in-vivo mindfulness of photos and slowing the pace down

3. Ending the session:

- Draw the session to a close by briefly **reviewing what you have covered** in the session.
- **Thank the participant** for their role in the session today.
- Once again check whether the participant has **any questions or queries** and answer in the best way you can.
- Ask the participant whether they have enough **phone credit** on the research mobile phone. **If they require a top-up, let the researcher know.**
- **Arrange a time and date for the next session** and write it on the appointment slip (Appendix 4) to be left with the participant (let support staff know if this is appropriate and has been agreed with the participant).

- ☐ Review today's session
- ☐ Thank participant
- ☐ Any questions?
- ☐ Arrange time, date and location of next session.

☐

Remind participant to continue to take photos

☐

Check phone credit - do they need a top-up?

4. After the session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.

Complete:

☐

Post-session frequency data sheet

2.3:

Session 3



Session 3

Session Overview



In this session, the therapist's role is to help the participant to clarify which photos/domains are very important and how closely these are being lived towards at the moment (using the scales to help - Appendix 5 & Appendix 6). By the end of this session, the participant will have identified two or three key areas in which they will endeavour to take more photos.

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Values Scales (Appendix 5 & 6)
- Post-session frequency data collection sheet (Appendix 3)
- Appointment slip (Appendix 4)



Activities:



1. Recap the previous session (5-10 minutes)

Ask the participant what they can remember from the last session. Work through any questions or queries that the participant may have that have arisen since the last session.

☐

Recap last session.

5. Review the photos (30-40 minutes)



Ask the participant to show you the photos that they have taken over the previous week. Provide assistance with the mobile phone to do this if required. Look through the photos together, asking the participant to describe the photos they have taken.

3. Group photos into values domains

As each photo is explored, ask the participant to consider which value domain they believe it relates to using the **values diagram** (Appendix 2).

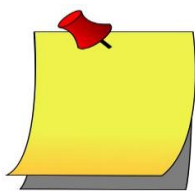
☐

Review photos

☐

Group photos into values domains

Note for therapist:



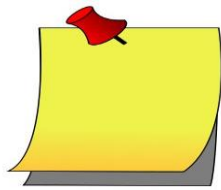
Being mindful of the photos in the moment

As with last week, really, really slow down the pace of the session and your speech when looking at the photos. Really slow down the pace of the session. Ask the participant to slow down their speech too when they are describing the photo. If you think that a photo has been talked through too quickly by the participant, ask them to describe the photo again, talking more slowly and really connecting with the words they are saying.



- As the photos are explored, really encourage the participant to tell you about all of the different elements that are in the picture.
- Ask the participant what comes up for them when they are describing the picture to you in that moment (do they notice any thoughts, feelings, physiological sensations, emotions, urges?)
 - ➔ If so, explore these further with the participant and be curious about how this experience is for them. You may ask questions such as **"how does your body feel when you have that thought?"** Encourage the participant to really connect with the emotional experience associated with exploration of their values.

Note for therapist:



*As noted in the previous session, the concept of talking about the photos in a slow pace may seem unusual to the participant and different from anything they have done before. Reassure the participant that this is likely to become less difficult as sessions progress and you practice exploring the photos in this way together. **Remind the participant of the reason for doing this, which is to really get to know their values and what the aspects of life in the photos mean to them.**

What if the client has not taken any photos?

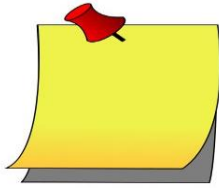
If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together – think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

For example, potential obstacles could be:

"I didn't know what to take pictures of" – if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" – consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (**for example – using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.**)

"I forgot to take the phone with me," – spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a reminder on a calendar, setting a reminder on their phone (or the research phone).



Note for therapist:

When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

☐ Recap rationale for in-vivo mindfulness of photos

4. Ending the session:

- Draw the session to a close by briefly **reviewing what you have covered** in the session.
- **Thank the participant** for their role in the session today.
- Once again check whether the participant has **any questions or queries** and answer in the best way you can.
- Ask the participant whether they have enough **phone credit** on the research mobile phone. **If they require a top-up, let the researcher know.**
- **Arrange a time and date for the next session** and write it on the appointment slip (Appendix 4) to be left with the participant (let support staff know if this is appropriate and has been agreed with the participant).

- ☐ Review today's session
- ☐ Thank participant
- ☐ Any questions?
- ☐ Arrange time, date and location of next session.
- ☐ Remind participant to continue to take photos
- ☐ Check phone credit - do they need a top-up?

5. After session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.

Complete:

☐

Post-session frequency data sheet

2.4:

Session 4



Session 4

Session Overview



In this session, the therapist and participant will identify under-developed areas on the values diagram (Appendix 2). Together, the participant and therapist will collaborate to see if there is scope to do some more in under-developed areas that are important. The aim is to help participants to broaden their values base and to identify and problem-solve barriers to engaging in aspects related to domains that are important.

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Values Scales (Appendix 5 & 6)
- Post-session frequency data collection sheet (Appendix 3)
- Appointment slip (Appendix 4)



Activities:



1. Recap the previous session (5-10 minutes)

Ask the participant what they can remember from the last session. Work through any questions or queries that the participant may have that have arisen since the last session.

☐

Recap last session.

2. Review the photos (20-30 minutes)



Ask the participant to show you the photos that they have taken over the previous week. Provide assistance with the mobile phone to do this if required. Look through the photos together, asking the participant to describe the photos they have taken.

3. Group photos into values domains

As each photo is explored, ask the participant to consider which value domain they believe it relates to using the values diagram (Appendix 2).

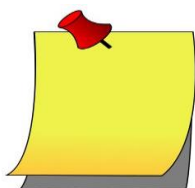
☐

Review photos

☐

Group photos into values domains

Note for therapist:



Remember to encourage the participant to be mindful of the photos in the moment



- As the photos are explored, really encourage the participant to tell you about all of the different elements that are in the photo.
- Ask the participant what comes up for them when they are describing the picture to you in that moment (do they notice any thoughts, feelings, physiological sensations, emotions, urges?)
 - ➔ If so, explore these further with the participant and be curious about how this experience is for them. You may ask questions such as **"how does your body feel when you have that thought?"** Encourage the participant to really connect with the emotional experience associated with exploration of their values.

What if the client has not taken any photos?

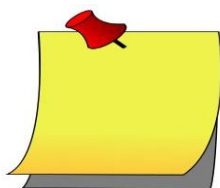
If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together - think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

For example, potential obstacles could be:

"I didn't know what to take pictures of" - if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" - consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (for example - using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.)

"I forgot to take the phone with me," - spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a reminder on a calendar, setting a reminder on their phone (or the research phone).



Note for therapist:

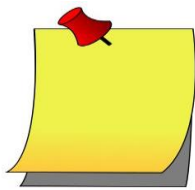
When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

4. Identifying practical barriers/under-developed domains

- Have a look at the values diagram (Appendix 2) together.
- Ask the participant if they can identify any gaps? Can they see any areas that they feel might need some more work?
- Together, discuss the gaps and explore whether there is any scope to do some more in under-developed areas that may be important to the participant.



Note for therapist:



For some participants, there may be practical barriers to engaging in activities they enjoy, such as transport, support or financial issues. Where appropriate (and with permission from the participant), liaise with supporters that the participant know well. Work together to see if there is a way that the participant may make steps towards doing more of the things that are important in their life.



- ☐ Recap being mindful of the photos in the moment
- ☐ Identify & explore practical barriers/under-developed domains

5. Ending the session:

- Draw the session to a close by briefly **reviewing what you have covered** in the session.
- **Thank the participant** for their role in the session today.
- Once again check whether the participant has **any questions or queries** and answer in the best way you can.
- Ask the participant whether they have enough **phone credit** on the research mobile phone. **If they require a top-up, let the researcher know.**
- **Arrange a time and date for the next session** and write it on the appointment slip (Appendix 4) to be left with the participant (let support staff know if this is appropriate and has been agreed with the participant).

- ☐ Review today's session
- ☐ Thank participant
- ☐ Any questions?
- ☐ Arrange time, date and location of next session.

- ☐ Remind participant to continue to take photos
- ☐ Check phone credit - do they need a top-up?

6. After session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.

Complete:

- ☐ Post-session frequency data sheet

2.5:

Session 5



Session 5

Session Overview



This session will extend the work covered in the previous session on barriers to engaging in aspects of under-developed domains that are important. The participant and therapist will work together to further clarify (in fine grain detail) their values. By the end of the session, the participant and therapist will have considered some committed action (doing the things that are important and taking photos as they go along).

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Values Scales (Appendix 5 & 6)
- Post-session frequency data collection sheet (Appendix 3)
- Appointment slip (Appendix 4)



Activities:



1. Recap the previous session (5-10 minutes)

Ask the participant what they can remember from the last session. Work through any questions or queries that the participant may have that have arisen since the last session.

☐

Recap last session.

2. Review the photos (20-30 minutes)



Ask the participant to show you the photos that they have taken over the previous week. Provide assistance with the mobile phone to do this if required. Look through the photos together, asking the participant to describe the photos they have taken.

3. Group photos into values domains

As each photo is explored, ask the participant to consider which value domain they believe it relates to using the values diagram (Appendix 2).

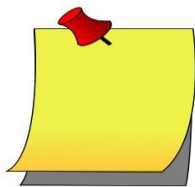
☐

Review photos

☐

Group photos into values domains

Note for therapist:



Remember to encourage the participant to be mindful of the photos in the moment



- As the photos are explored, really encourage the participant to tell you about all of the different elements that are in the photo.
- Ask the participant what comes up for them when they are describing the picture to you in that moment (do they notice any thoughts, feelings, physiological sensations, emotions, urges?)
 - ➔ If so, explore these further with the participant and be curious about how this experience is for them. You may ask questions such as **"how does your body feel when you have that thought?"** Encourage the participant to really connect with the emotional experience associated with exploration of their values.

What if the client has not taken any photos?

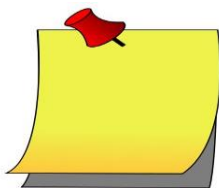
If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together - think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

For example, potential obstacles could be:

"I didn't know what to take pictures of" - if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" - consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (for example - using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.)

"I forgot to take the phone with me," - spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a reminder on a calendar, setting a reminder on their phone (or the research phone).



Note for therapist:

When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

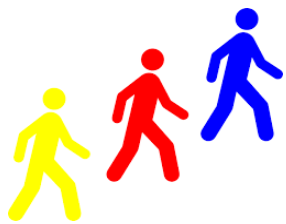
4. Overcoming practical barriers:

- Have a look at the values diagram (Appendix 2) together.



- Ask the participant if they can identify any gaps? Can they see any areas that they feel might need some more work? If so, collaboratively explore how the participant may work towards doing more things in that domain to help them to live towards their life values.
- Together, discuss the gaps and explore whether there is any scope to do some more in under-developed areas that may be important to the participant.

5. Moving towards Committed Action



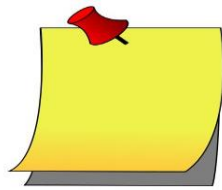
- Discuss with the participant the possibility of taking steps towards doing an activity related to one of their values.
- Ask the participant if they can think of anything important to them that they would particularly like to do, that they are perhaps not currently doing?



For example: Learning may be an important value for the participant. The participant may wish to go to college/enrol on a course, although may not yet have made the first steps towards doing this. Through discussion with participant, spend time breaking down the notion of going to college into small steps. For example, the first step may be to have a look at courses on the internet. The next step may be to go to college and pick up a prospectus and so on.

- ☐ Recap being mindful of the photos in the moment
- ☐ Explore barriers/under-developed domains
- ☐ Explore moving towards committed action.

Note for therapist:



For some participants, there may be practical barriers to engaging in activities they enjoy, such as transport, support or financial issues. With permission from the participant, liaise with supporter(s) that the participant knows well and work together to see if there is a way that the participant may make steps towards doing more of the things that are important in their life.

4. Ending the session:

- Draw the session to a close by briefly **reviewing what you have covered** in the session.
- **Thank the participant** for their role in the session today.
- Once again check whether the participant has **any questions or queries** and answer in the best way you can.
- Ask the participant whether they have enough **phone credit** on the research mobile phone. **If they require a top-up, let the researcher know.**
- **Arrange a time and date for the next session** and write it on the appointment slip (Appendix 4) to be left with the participant (let support staff know if this is appropriate and has been agreed with the participant).

☐

Review today's session

☐

Thank participant

☐

Any questions?

☐

Arrange time, date and location of next session.

☐

Remind participant to continue to take photos

☐

Check phone credit - do they need a top-up?

5. After session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.

Complete:

☐

Post-session frequency data sheet

2.6:

Session 6



Session 6

Session Overview



In this session, the aim is to consider future planning and living towards values in the short and longer term.

Materials (Things you will need):

- Treatment manual (this document)
- Pens
- Values work sheet (Appendix 1)
- Values Diagram (Appendix 2)
- Values Scales (Appendix 5 & 6)
- Post-session frequency data collection sheet (Appendix 3)



Activities:



1. Recap the previous session (5-10 minutes)

Ask the participant what they can remember from the last session. Work through any questions or queries that the participant may have that have arisen since the last session.

☐

Recap last session.

2. Review the photos (20-30 minutes)



Ask the participant to show you the photos that they have taken over the previous week. Provide assistance with the mobile phone to do this if required. Look through the photos together, asking the participant to describe the photos they have taken.

3. Group photos into values domains

As each photo is explored, ask the participant to consider which value domain they believe it relates to using the **values diagram** (Appendix 2).

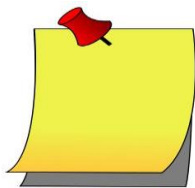
☐

Review photos

☐

Group photos into values domains

Note for therapist:



Remember to encourage the participant to be mindful of the photos in the moment



- As the photos are explored, really encourage the participant to tell you about all of the different elements that are in the photo.
- Ask the participant what comes up for them when they are describing the picture to you in that moment (do they notice any thoughts, feelings, physiological sensations, emotions, urges?)
 - ➔ If so, explore these further with the participant and be curious about how this experience is for them. You may ask questions such as **"how does your body feel when you have that thought?"** Encourage the participant to really connect with the emotional experience associated with exploration of their values.

What if the client has not taken any photos?

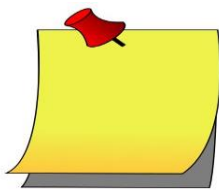
If the participant has not taken any photos, spend some time exploring the obstacles to taking photos with the participant. Once the obstacles have been identified, spend some time problem-solving together - think together about how the participant might be able to overcome the obstacles that prevented them from taking photos this time.

For example, potential obstacles could be:

"I didn't know what to take pictures of" - if so, look together at the participant's weekly schedule or the values diagram (Appendix 2) for ideas.

"I'm not able to get to the places I want to go to" - consider some practical solutions, or ways of taking photos of things that represent the same values but are more accessible (for example - using the internet, google, you-tube to watch videos/research/look at pictures of valued aspects of life.)

"I forgot to take the phone with me," - spend some time thinking with the participant about how they usually help themselves to remember things. For example, post-it reminder notes, making a note in their diary, writing a reminder on a calendar, setting a reminder on their phone (or the research phone).



Note for therapist:

When exploring obstacles, be mindful to do this in a non-judgemental way. Strive to make the venture collaborative, encouraging the participant to generate potential solutions. Perhaps incorporate humour. With the participant's permission, you could ask a supporter that they know well to join the session and have a think about how to overcome obstacles. The aim here is **not** to punish the participant for not taking photos. Rather, the process should strive to motivate the participant to feel motivated to take photos of things that are important in life.

4. Future planning: living towards values



- Have a look at the **values diagram** (Appendix 2) together. Over the last six weeks, the participant and therapist will have become more familiar with the most important domains.
- Ask the participant to have a think about the values domains that are really important to them.
- Can the participant identify values/values domains that they would especially like to work towards in the short term?
- Are there any values/values domains that the participant would like to work towards in the long term?
- Explore the long and short values with the participant. You can do this by helping the participant to think about how they may go about living towards their values in the short/long term.
 - Would anything need to change?
 - Can the participant think of any particular things they might need to consider in order to move towards their values in the future?



- ☐ Identify values for short term focus
- ☐ Identify values with a longer term focus.
- ☐ Explore the values with the participant

5. Finishing Therapy (Review session 5-10 minutes)

Finish the session by congratulating the participant for completing the Catching What Matters course and outlining their achievements and all of the good work they have done.

- Remind the participant that they should continue to reply to the text messages as they have been doing every 3 days for the next couple of weeks.



- Let the participant know that they should **stop taking photos from now**.

- Remind the participant/supporter that the researcher will be in touch soon to do a follow-up visit. During this visit, the participant will receive payment as a thanks for their participation.



- ☐ Outline achievements
- ☐ Let the participant know that the researcher will be in touch soon to do a follow-up visit.
- ☐ Check phone credit - do they need a top-up?

6. After session:

Once the session has finished, complete the '**post-session frequency data collection sheet**' (Appendix 3). Try to do this as soon as possible after the end of the session, to ensure the session is fresh in your mind.

Complete:

- ☐ Post-session frequency data sheet



Part Three:

Appendices



Appendices

Appendix i: Session Outline (optional for use to guide through session structure)

Appendix 1: Values worksheet

Appendix 2: Values diagram

Appendix 3: Post-session frequency data collection sheet

Appendix 4: Appointment Slip

Appendix 5: Values Scale I (How important is this value to me?)

Appendix 6: Am I working towards this value in day-to-day life?

Session Outline

Appendix i: Optional for use to guide session structure

COVERED?

Part 1: Introduction

- ☐ Introduce self
- ☐ Remind participant of clinician's role (to meet with them for 6 sessions to talk about the photos they have taken on the mobile phone)
- ☐ Recap limits of confidentiality (duty bound to follow safeguarding procedures if concerns become apparent).

Part 2: Practical aspects of taking photos

- ☐ Has participant taken photos this week?
- if not, is there anything we can do to help them?

- ☐ Has participant brought photos with them?
- ☐ How did the participant find taking photos of things they value in life?

- ☐ Any problems with:
 - Mobile phone/signal
 - Texting (receiving/replying)
 - Remembering to reply

Part 3: Looking at the photos together

- ☐ What types of things participant take photos of? (Do they fall into any of the ACT domains? - Complete ACT Values worksheet)
- ☐ Discuss the content of the photos taken (Be curious: e.g. 'What made you choose to take this picture? What's important to you about what's in this picture?')
- ☐ How many photos taken in total?

Part 4: Bringing the session to a close

- ☐ Thank participant for attending & check whether they have any questions.
- ☐ Remind participant to continue to take photos of valued aspects of life.
- ☐ Are they OK for phone credit? (Do they need a top up?)

Values

Appendix 1: Values Worksheet



are things we care about and think are important.



Values are different from goals (we can achieve our goals). Values are more like compass directions that we want to head in.

For example, we may have a **goal** of going for a jog. Our **value** would be exercise and keeping fit.



The things listed below are important for some people. Think about what is important to you, and what might be your life values.

Health

How do I want to look after myself?



FAMILY

What kind of relationships do I want with my family?

Romance



What kind of partner do I want to be?
What kind of relationship would I want to be part of?

Community



(Being part of something)

What kind of environment do I want to be a part of?
How do I want to contribute to my community?

Friends



What sort of friend do I want to be?



Spirituality



(What's the world all about?)

What kind of relationship do I want with the world around me?
(e.g. God/Nature/The earth?)

Daytime Activities

(e.g. work/college)



What jobs/courses are worth doing and important to me?

Leisure/Chilling Out



How would I like to enjoy myself?
What helps me relax?
When do I have the most fun?

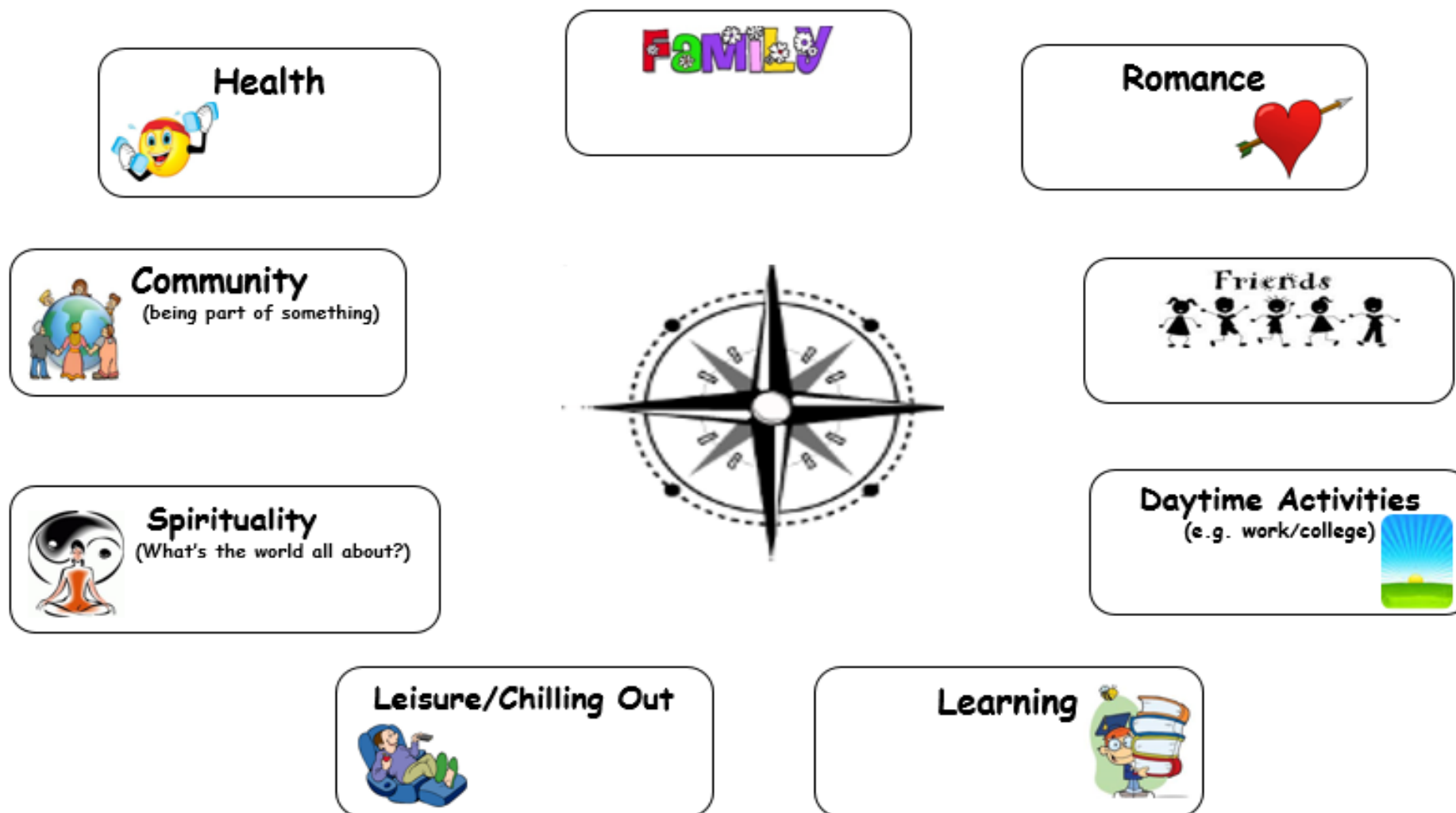
Learning



What would I like to learn more about?

Confirm date & time of next session (let support staff know if appropriate).

Catching What Matters Manual Appendix 2: Values Diagram





Post-Session Frequency data Collection:



Note:

☐ Did participant attend?*

(*if not, note reason for non-attendance)

☐ Was a supporter present (if applicable?)

(If so – comment on level of supporter involvement required for participant to engage)

☐ Number of photos taken in total: ☐

☐ Photos taken from a broad domain variety?

☐ Any problems/queries to note?

☐ Was there one particular photo that stood out in particular as most helpful in managing participant's worries?

☐

Appendix 3: Post-Session Frequency Data collection sheet

- Phone credit – do they need a top up? Yes / No
(If top up required, let Natalie know).

Anything else?



If you would like to make a note of anything not covered in the questions above, please do so below:

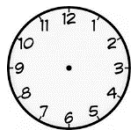
[illegible]

Appendix 4: Appointment Slip

The next session to talk about the photos I have taken with.....(Catching What Matters therapist) will be on:



Date:



Time:



Place:



Remember to keep replying to the text messages every 3 days.



Remember to take photos of things that are important in your life.



See you then 😊

How important is this value to me?



Not
important
at all



Not very
important



In the
middle



A bit
important



Very
Important

**Am I working towards this value in
day-to-day life?**



**Not
at all**



Not much



**In the
middle**



A bit



A lot

Appendix – U – End of Intervention GP Letter Template



Miss Natalie Boulton
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
43 College Road
Bangor
Gwynedd
LL57 2DG

Dr Jonathan Williams
Senior Clinical Psychologist
Denbighshire County Council
County Hall
Wynnstay Road
Ruthin
LL15 1YN

<Insert GP Name>
<Insert GP Address>

Date: <Insert Date>

Re: <Insert participant name>
Address: <Insert participant address>

Further to my previous letter dated <insert date>, I am writing to let you know that <participant name>'s participation in our research project: *"Life through a lens: A pilot study investigating auto-photography and anxiety amongst people with learning disabilities"* is now complete.

Once the research project is complete (estimated to be in summer 2016), I will meet with <participant name> to discuss the findings and provide an accessible summary of the results.

Please do not hesitate to get in touch if you have any questions.

Yours Sincerely,

Natalie Boulton
(Trainee Clinical Psychologist)

Dr Jonathan Williams
(Senior Clinical Psychologist)

Professor Robert Jones
(Programme Director, North Wales Clinical Psychology Programme & Consultant Clinical Psychologist).

CC: <referrer>